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The Longitudinal Australian Study of Students with Autism (LASA)

FINAL REPORT

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The education and participation trajectories of students on the autism spectrum

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Autism CRC

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

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A note on terminology

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

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

The CRC and this specific project were both set up and named when "with autism" was a preferred term, hence "with autism" remains used in this report when referring to the CRC or the specific project name.

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1. Introduction

Autism is characterised by differences in communication and social functioning, which have a pervasive and life-long impact, and by the presence of repetitive behaviours and special (narrow and deep) interests (Howlin et al., 2013). While there are consistent core features of autism as outlined in diagnostic systems such as the *Diagnostic and Statistical Manual 5th edition* (DSM-5; American Psychiatric Association, 2013), autism is a highly heterogeneous condition. Profiles of autism characteristics are highly variable both within and between people who meet the criteria for a diagnosis of autism. For example, one person on the autism spectrum may be highly verbal and talk a great deal about a particular topic of interest to them while another person on the autism spectrum may not speak at all and may show very little interest in other people. The same highly verbal person on the spectrum may have very marked narrow interests and find change challenging, while another highly verbal autistic person may demonstrate only mildly narrow interests and repetitive behaviours. Therefore, while we take a group approach in this study, we wish to emphasise that it is critical that each individual on the autism spectrum is respected as an individual who has their own profile of strengths and challenges, and that assumptions should not be made based upon diagnosis.

Historically, children with disabilities or special needs were rarely educated and were often classified as ‘ineducable’ or even ‘untrainable’. In the 1960s, in Australia and internationally, the perspective shifted to one that recognised that all children could learn and benefit from education. This resulted in the establishment of special schools for children with disabilities, including for children on the autism spectrum. Parents usually set up the schools, and children with special needs were educated separately in a specialist setting. The prevailing lens for viewing disability at the time was the medical model in which characteristics of autism are described as deficits and deviations from the norm that needed to be remediated. The best setting at the time was considered to be a specialised and segregated school. As a result, for the next two decades, students with disabilities in Australia and internationally were largely educated in segregated settings. The only children with disabilities in mainstream schools were those who managed to somehow fit in and survive. At that time, it was not considered to be the job of schools to accommodate diverse learners.

In the mid-1990s opinion about where children with disabilities, including autism, should be educated swung towards the education of all children together in their local school. This was, and is, considered by many to be a human rights issue, with inclusion in mainstream education described as a fundamental human right. The idea that all children should be educated together was enshrined in the Salamanca Statement (United Nations Educational, Scientific and Cultural Organization [UNESCO], 1994), which provides the philosophical underpinning for the inclusion of students on the autism spectrum in regular education.

As a result, special school placements in some countries dropped as students were more likely to be placed in mainstream settings (Graham et al., 2010). However, in reality, rather than being included in mainstream classes, students with special needs were spending all or part of their time in separate classrooms on the mainstream school campus; Pellicano et al. (2018) suggest that formal recommendations and regulations guiding inclusion remain well ahead of attitudes and practice. In addition, outcomes for students on the spectrum continue to be poor relative to their peers not on the autism spectrum, including other groups of diverse learners. In Australia there has been a growth in demand for special education places not only driven by a growth in numbers of students diagnosed with a disability (Graham et al., 2010) but also reflecting a perception of a lack of adequate support for students with disabilities in mainstream classes (Lilley, 2013). The medical model of disability continues to dominate diagnostic processes and service provision and the debate between the medical and social model of disability continues. This has relevance for schools and school systems in that the perception of and attitude towards diverse learners determine the extent to which the student on the spectrum is expected to conform to the school’s norms, whatever they may be (medical model); and the extent to which the school adapts to, accommodates, and supports the student on the autism spectrum (social model).

1.1 Participation

Participation is defined by the World Health Organisation (WHO) as involvement in life situations and is considered an indicator of quality of life. It is now recognised that participation is a dual construct that includes both attendance (i.e., being there) and involvement in an activity (Imms et al., 2016). Over the last two decades there has been a focus on understanding participation and factors that influence a person’s participation. Participating in the school experience provides students not only the opportunity to engage in learning activities but also opportunities to develop social and life skills. Since the UNESCO's Salamanca Statement (1994) there has been a commitment to inclusive schooling and this has led to an increase in the number of children on the autism spectrum attending schools. However, just because children are physically attending school does not mean they are involved and engaged in the school experience. Truly inclusive practice involves supporting students to actively participate in their school community (Lynch & Irvine, 2009).

The number of students in educational systems with a diagnosis of autism is rising. For example, currently in Queensland schools in 2021, 3.4% of all students have a verified diagnosis of an autism spectrum condition while specialist schools for autistic students, such as The Sycamore School in Queensland, have long waiting lists for places. There is evidence that learning in mainstream educational environments presents a substantial challenge for many individuals on the autism spectrum. A 2018 survey of the educational needs in children on the autism spectrum in Australia reported that most (92.3%) had some form of educational restriction (e.g., attending a special class). Of those attending school, 77% were 'having difficulty' at school, with the majority of difficulties being social, communicative, and cognitive (Australian Bureau of Statistics, 2019). Although these difficulties are recognised both academically and clinically as potential barriers to learning, there is scant research into the influence of each of these factors on educational participation and achievement.

Providing students on the autism spectrum with appropriate educational supports and other interventions during their schooling is critical to securing higher levels of participation and independence in adult life. The long-term impact of not providing appropriate educational supports at an early age is becoming increasingly apparent.

1.2 Academic, educational, and vocational outcomes

The academic achievement of individuals on the autism spectrum has received little attention from researchers despite the importance placed on this by schools, families, and students on the autism spectrum. While academic achievement of children and young people on the spectrum is clearly an important topic, it would seem that research is scant: in a 2015 review of the relevant research literature, Keen et al. identified only 19 studies of factors related to the academic achievement of children and adolescents on the spectrum. Adolescents and individuals with lower IQ scores were under-represented in the research and few studies focused on environmental factors related to academic success, with most studies conducted in artificial clinical settings rather than in schools. Research into levels of academic achievement between groups of individuals indicated tremendous variability in general academic achievement across the spectrum. In addition, research into predictors of academic achievement focused on child characteristics such as intelligence or language ability, which tells us little about the programs or strategies that most directly influence academic achievement and have direct relevance for practice. Keen et al. (2016) highlighted that there is variability also within profiles for individuals on the spectrum with unique profiles of relative strengths and weaknesses. They stress the importance of individualised assessments to aid in educational programming.

Keen et al. (2016) emphasised that there are significant gaps in current knowledge about predictors and correlates of academic achievement, and that addressing these gaps may help to address the reported academic underachievement of students on the spectrum. In particular, research is needed in relation to adolescents and individuals with lower IQ scores and the impact of a range of environmental factors on academic achievement. Additionally, there is a need for research to focus on bridging the gap between understanding the nature of academic achievement for individuals on the spectrum and working with educators to investigate and create environments and practices that support individuals on the autism spectrum to achieve academic success. Further research on child-related and environmental factors that predict academic achievement is also required.

On finishing school, future prospects for young adults on the spectrum appear to be poor, with many being unemployed, experiencing mental illness, and having reduced independence. A systematic review of adults on the spectrum classed outcomes in social integration and independence as ‘poor’ or ‘very poor’, with 50% or more remaining fully or largely dependent on parents or carers and requiring significant support for further education, living arrangements, and employment (Magiati et al., 2014). Unemployment is higher in those on the autism spectrum compared to adults with speech-language impairments and intellectual disability more broadly, indicating that the combination of social, communication, and behaviour challenges places these individuals at heightened risk for poor long-term community participation.

Despite the documented difficulties that children on the spectrum experience in school and the well-recognised need to improve educational outcomes, there is limited information about the participation and educational trajectories of children on the autism spectrum and how this influences adult outcomes. It is also unknown which child, family, and environmental factors may influence these trajectories over time. Information about educational trajectories and outcomes, and the way these interact with child and family characteristics (including those created as a result of their education), is needed to enable tailoring of interventions and educational approaches for individual children and young people on the autism spectrum and their families as they progress through and transition from their education. We know that the characteristics of autism – in particular, social communication differences, difficulty making sense of the world, and a preference for routine or similarity – can make transition into new environments particularly challenging for individuals on the autism spectrum. There is a clear need for more research to provide information about key factors in education, including transition to school, participation, and different educational environments, in order to understand the experience of children on the autism spectrum and explore the potential impact on their development.

The heterogeneity that exists amongst individuals on the autism spectrum and their communities (e.g., caregivers, teachers, allied health clinicians, school executive) makes cross-sectional research challenging, even with large participant samples, particularly in non-clinical settings. An added complication is the wide variety of interventions and programs accessed by those on the spectrum, their families, and caregivers. Further, the high levels of parenting stress relative to parents of other groups (see review by Barosso et al., 2018) which may be impacted by navigating interventions, responding to stigma, and secondary challenges such as reduced capacity to work and financial implications, may also impact on the course and development of children on the spectrum. Longitudinal research designs enable researchers to avoid or reduce the limitations of cross-sectional research by studying within-person and within-environment change over time, including both parent and child factors such as parenting stress. This is particularly important for research relating to educational settings, where cohort effects can be observed on factors such as school engagement, participation, and outcomes – areas that are, at present, under documented and under researched.

1.3 Definitions

Autism. Throughout this report we use the term ‘autism’ to refer to children who had received a diagnosis consistent with diagnostic criteria for autism spectrum conditions as outlined in the 4th or 5th editions of the *Diagnostic and Statistical Manual* of the American Psychiatric Association or the 10th edition of the *International Classification of Diseases* (ICD-10). The publication periods of these editions coincide with the age range of participants in the study, and are routinely used by doctors, psychologists, and allied health professionals involved in the diagnosis of children on the autism spectrum in Australia. Generally, in the report we use person-first language (person on the autism spectrum) consistent with the approach used in the UN Convention on the Rights of Persons with Disabilities; however, we acknowledge the preference for many in the autistic community for identity first language (e.g., autistic person) and at times have used a mix of terms.

Participation. Although it is acknowledged that this term is widely debated, in this study we adopted WHO’s International Classification of Functioning, Disability and Health (ICF; WHO, 2001) definition of participation as ‘engagement in life situations’. This term is consistent with the constructs measured in the Participation and Environment Measure – Child and Youth, used in the study.

1.4 Study aims

The primary aim of this study, entitled the Longitudinal study of Australian Students with Autism (LASA), was to document the educational and participation trajectories and outcomes of Australian students on the autism spectrum over a 6-year period. The study design allowed for the inclusion of periods of change and transition such as starting school (4-5-year-old children) and moving from primary to high school. The secondary aim was to examine personal factors (e.g., student skills) and environmental factors (e.g., school setting, community supports) associated with varied trajectories and outcomes.

1.5 Research questions

The research questions set at the outset of the LASA (2015) were:

1.5.1 Participation

1. How do types and levels of participation at school change over time?
2. What aspects of education programs facilitate or hinder participation at school?
3. What child and family characteristics facilitate or hinder participation at school?

1.5.2 Education

1. What types of educational programs/interventions do children and their families access?
2. What are the trajectories of educational outcomes over time?

1.5.3 Child outcomes

1. Do autism subtypes (identified in program 1.3) predict educational outcomes for children over time?
2. Do particular child characteristics (language, social, cognitive, or behavioural) predict educational outcomes for children?
3. Does type and level of child participation in educational programs predict educational outcomes over time?

To ensure that the LASA data provide the maximum benefit to the autistic and autism communities, other research questions have been explored during the data collection period whilst ensuring that data for these key research questions are preserved. For example, there have been a series of studies exploring anxiety in autism, a number of which were conducted by two Autism CRC scholars and these are summarised in the LASA publication output section in this report.

2. Research Design and Methods

2.1 Study design

The LASA is a 6-year prospective longitudinal study capturing quantitative data on educational and participation outcomes from two cohorts of children on the autism spectrum, who were aged 4-5 years and 9-10 years at time of entry into the study (2015). These two time points were chosen in order to capture information about participants at key transition points at the start of the study: transition into school and transition between primary and high school. The choice of time points and age range also potentially enabled comparison between the younger cohort at the end of the 6 years of data collection with the data from the first year for the older cohort. Parents/caregivers and education professionals (teachers and principals) provided information annually about the children’s educational and participation progress, as well as about factors hypothesised in the research literature to be associated with differing trajectories and outcomes. The project was managed by the LASA research team comprised of staff from Griffith University, Autism Centre of Excellence, and partners from industry.

2.2 Study population

Participants were recruited from all states and territories in Australia. In 2015 the population of Australia was approximately 23 million people, including 3,750,973 school-aged children between 2014-2015 (ABS, 2016). With a conservative estimated prevalence of 1 in 100 children, the estimated number of all school-aged children on the autism spectrum during the same time period was 37,509.

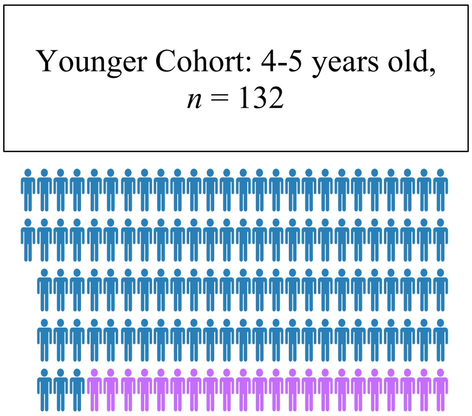
The primary participant group was caregivers of children on the autism spectrum aged 4-5 years or 9-10 years between January and November of 2015. Each child was required to have received a clinical diagnosis of autism by health professionals in the community, documented in a written report, with a copy provided to the research team. Children with additional medical diagnoses (e.g., seizure disorders, intellectual disability) were included in the study to ensure the study sample reflected the clinical population as accurately as possible. Parents/caregivers were asked to complete questionnaires via an online platform. These tasks assumed skills in spoken and written English, but no exclusion criteria were adopted, with participants self-selecting.

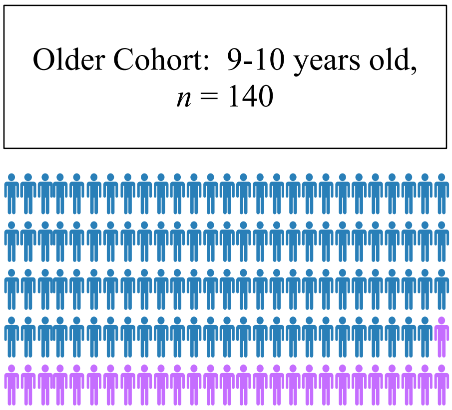
The second key participant group was educational professionals, namely, principals and teachers working with each child in the study in formal school settings, who consented to participate in the study. No additional exclusionary criteria were applied.

2.3 Participant selection and recruitment

Parent/caregiver participants were recruited nationally after receiving information about the study 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 registered to participate in the study through an internet link. Parents/caregivers who registered were contacted by a research team member and if their child was eligible and they agreed to participate, they were sent an online parent/caregiver questionnaire. At recruitment, parents were asked to provide copies of any diagnostic or educational/school or assessment reports that they were prepared to share with the research team.

The sample for the initial year of the LASA was 272 children, 132 who were aged 4-5 years at recruitment and 140 who were aged 9-10 years at recruitment. The overall sample was 20% female (shown in purple) and 80% male.





Beginning in the second year of the study, if parent/caregiver consent was given, the principal of their child’s school was contacted and asked if they and the child’s teacher would complete a survey. The principals’ survey was removed in 2018 as it was felt that this was a barrier to schools participating in the study. The rate of teacher completion of questionnaires increased once the step involving principals was removed and the process for schools streamlined as a result. However, in all school data collection years, the principal was asked to consent to the research team contacting the child's teacher. If this consent was given the child's teacher was contacted and invited to complete an online survey about the child's progress and participation at school.

2.4 Data collection procedure

Parents were asked to complete online surveys annually for 6 years (2015 – 2020), comprising six time points (T1-T6). Following recruitment, parents were emailed a link to the online survey. Parents were then contacted annually and asked to complete either an extended online survey (at T3, T5, & T6) or an abbreviated online survey (at T2, T4).

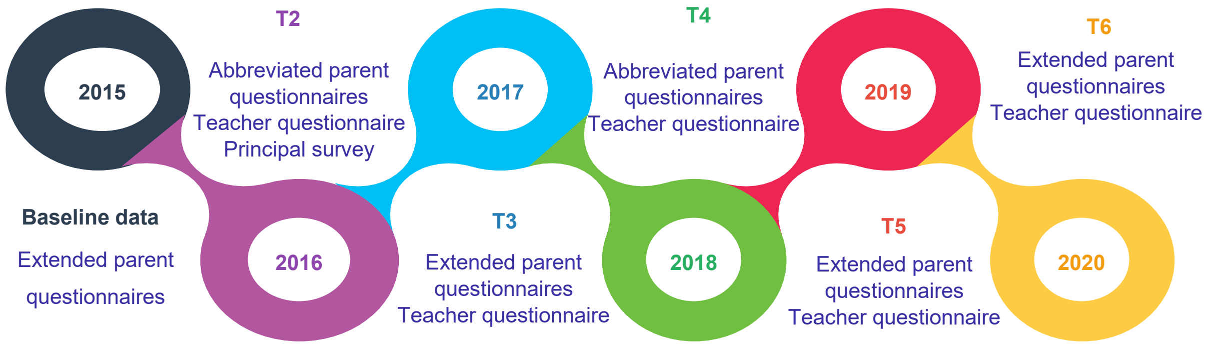
Where consent was given, the child's school was contacted annually and the child's teacher (and in T2 & T3 only) and the school principal were asked to complete a survey about the child or school, respectively. At each time point, parents, teachers, and principals (T2 & T3 only) were given one month to complete the questionnaire. During that period, they could stop and start the survey as many times as they liked as responses were saved online. Participants who did not complete the surveys in the required time received reminders via email and/or a phone call from the Project Coordinator to offer assistance and to confirm their willingness to continue in the study.

2.5 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 systematic review of the literature (Keen et al., 2016). See Table 1 for parent measures. The length of the questionnaire was monitored in order to minimise participant burden, with the abbreviated questionnaire (at T2 & T4) taking approximately 30 minutes to complete and the extended questionnaire (at T1, T3, T5, & T6) taking approximately 1.5 – 2 hours to complete.

An overview of assessments (including detail on their reliability and validity), and the time points at which they were collected, is provided in Figure 1. The parents completed questionnaires focussing on demographics, the primary outcome variable (child participation), and adaptive behaviour at each timepoint. The secondary outcome and other explanatory factors were measured at T1, T3, T5, and T6. Where consent was given by the parent, principal, and the teacher, teacher data were collected on the primary academic outcome from T2. From T4, the principal was asked for consent only and was not required to complete a survey as most of the information requested was available on the school websites.

Figure 1: LASA data collection timeline



When parents consented to school input, the principal was asked at T2 and T3 to complete a questionnaire about both whole-school and individualised programs or approaches available or being used for autistic children in their school. Where the principals consented to the teacher being contacted, the child's teacher was approached annually (T2-T6) and asked to complete a range of online questionnaires, as detailed in Table 2. The questionnaire pack for teachers consisted of a questionnaire gathering information on the available support for transitions into their school, use of Individual Education Plans (IEPs), accommodations for testing and assessments and social skills support, a questionnaire (ACES) on academic functioning for their student (compared to their peers), and the Strengths and Difficulties Questionnaire, which gathers information on the students' emotional, behavioural, and social profile.

Table 1: Parent survey measures used in the LASA and their published reliability statistics (from Roberts et al., 2018; protocol paper)

	Time	Instrument	Time to complete	Reliability
Child and family demographic information	T1, T2, T3, T4, T5, T6	Family History survey		NA
Participation	T1 (Intake or 5th birthday for those under 5 at intake), T2, T3, T4, T5, T6	Participation and Environment Measure – Child & Youth (PEM-CY)	40 mins	Internal consistency1: .59-.91 Participation frequency: .59-.70 Participation involvement: .72-.83 Environmental Supportiveness: .67-.91 Test-retest reliability1 Participation frequency: .58-.84 Participation involvement: .69-.76 Desires change: .76-.89 Environmental Supportiveness: .85-.95
Child, family, intervention/ program characteristics	T1, T3, T5, T6 Shortened version for T2, T4	Family History survey	60 mins	NA
Child's diagnosis	T1	Social Communication Questionnaire (SCQ) Lifetime	10 mins	Internal consistency2 (α) = .93 Test-retest2 = .81
Child's diagnosis	T4	Social Communication Questionnaire (SCQ) Current	10 mins	
Child outcomes	T1, T3, T5, T6	Children's Communicative Checklist (CCC-2)	15 mins	Internal consistency4 (α): .73-.88 Inter-rater reliability4: .61-.83
Child outcomes	T1, T2, T3, T4, T5, T6	Vineland (VABS-II)	45-90 mins	Internal consistency3 (α) Communication: .84-.93 Daily Living Skills: .86-.91 Socialisation: .84-.93 Test-retest across domains3: .76-.92

	Time	Instrument	Time to complete	Reliability
Child outcomes	T1 for those with fewer than 50 words	Pragmatic Profile of Everyday Communication	45 mins	NA
Child outcomes	T1, T3, T5, T6	Developmental Behaviour Checklist Parent Version	20 mins	Internal consistency4 (α): .73-.88 Inter-rater reliability4: .61-.83
Child outcomes	T1, T3, T5, T6	Short Sensory Profile	10-15 mins	Internal consistency7: .57-.92 Test re-test7: .83-.92 Inter-rater reliability7: .49-.89
Child outcomes	T2, T3, T4, T5, T6	Anxiety Scale for Children with Autism Spectrum Disorder	5 mins	Internal consistency8 (α): .85-.91 Separation anxiety: .87 Uncertainty: .88 Performance: .89 Anxious arousal: .88 Test re-test8 (α): .84
Child outcomes	T3, T4, T5, T6	Lerner Measure of Thriving	5 mins	
Child outcomes	T4, T5, T6	Bullying Questions (NLTS)	1 min	NA
Family factors	T1,	Family Outcome survey revised version	40 mins	Internal consistency9 (α): .73-.91
Family factors	T1, T3, T5, T6	Parental Stress Index-4-Short Form	10 mins	Internal consistency10 (α): .98 Child: .96; Adult: .96 Test re-test10: .96 Child: .63; Parent: .91

Table 2: School measures used in the LASA and their published reliability statistics (from Roberts et al., 2018, protocol paper)

Instrument	Measured at	Captures	Domains	Reliability
Secondary outcome variable: Academic Competence Evaluation Scales (ACES) 23	T1, T2, T3, T4, T5, T6	Academic functioning of student	Academic skills (reading/language arts, mathematics, critical thinking) Academic enablers (interpersonal skills, engagement, motivation, study skills)	Internal consistency1 (α): .94-.99 Test re-test1: .88-.97
Strengths and Difficulties Questionnaire – Teacher (SDQ) 36	T1, T2, T3, T4, T5, T6	Profile of strengths and difficulties	Emotional symptoms Behavioural difficulties: Hyperactivity Peer problems Prosocial behaviours	Internal consistency2: .73 Test re-test reliability2: .62
Teacher survey (compiled from National Longitudinal Transition Study-2, 20 US Department of Education and other sources, including the Longitudinal Study of Australian Children (LSAC) 21	T1, T2, T3, T4, T5, T6	Student behaviours, teaching practices, and school environment		N/A
Principal Survey (compiled from National Longitudinal Transition Study-2, 20 US Department of Education and other sources, including LSAC) 21	T1, T2, T3, T4, T5, T6	Whole-school context in relation to programs/approaches used to educate children on the autism spectrum		N/A

2.5.1 Primary outcome measure

The primary outcome measure was the parent completed measure of participation. Each year, caregivers were invited to complete the Participation and Environment Measure for Children and Youth (PEM-CY; Coster et al., 2011). The PEM-CY is a caregiver questionnaire that measures participation of children and youth (5-17 years) and includes 25 items across home, school, and the community. This is a parent-rated assessment that addresses the broader definition of participation outlined by the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY; WHO, 2007). The ICF-CY recognises that participation includes not only attending an activity but also the level of involvement in the activity. The PEM-CY examines the number of activities in which children participate, the frequency of their participation, and their level of involvement in the activities. The scale is completed by parents/caregivers who report on items that represent activities typically performed in that environment (i.e., home, school, community) and that address content from ICF-CY chapters ‘Activities’ and ‘Participation’. For each item, parents/caregivers report on their child’s participation over the last 4 months.

The 25 questions in the PEM-CY are divided across home (10 items), school (5 items) and community (10). The home setting items address activities related to leisure (e.g., ‘playing computer and video games’, ‘indoor play and games’), personal care and responsibility (e.g., ‘personal care’, ‘household chores’, ‘homework’), and socialising (e.g., ‘getting together with other people’, ‘socialising using technology’). The school setting items address activities related to daily activities (e.g., ‘classroom activities’, ‘getting together with peers outside of class’), organised activities (e.g., ‘school teams, clubs and organisations’, ‘field trips and school events’), and roles (e.g., ‘special roles at school’). The community setting items address activities related to organised activities (e.g., ‘organised physical activities’, ‘classes and lesson’, ‘religious or spiritual gathering’), social activities (e.g., ‘neighbour outings’, ‘overnight visits or trips’), and work-related activities (e.g., ‘working for pay’).

For each item, parents/caregivers are asked to rate how often their child participated in the activity over the last 4 months on an 8-point scale (0 = *never* to 7 = *daily*) and how involved their child was when participating in one or two activities of this type that they do most often, on a 5-point scale (1 = *minimally involved* to 5 = *very involved*). This provides three summary outcomes for each setting, the number of activities they participated in over the last 4 months (max score: home = 10, school = 5, community = 10) with higher scores indicating a greater range of activities. The second outcome is the average frequency of participation, that is, on average, how often the child participates in activities that they actually do (max score = 7), with higher scores indicating greater frequency across activities in a given setting. The third outcome is the average involvement, that is, the how involved or engaged the child was in the activities they attended (max score = 5), with higher scores indicating greater involvement across activities in a given setting.

As reported in Table 1, this measure reports moderate to good reliability and ability to detect differences in groups, and is suitable for large-scale studies (Coster et al., 2011). Test-retest reliability is reported to be good for home (0.84) and community (0.79) and moderate for the school setting (0.58; Coster et al., 2011). In a paper reporting on Year 1 to Year 3 LASA data for the older cohort, our team (Simpson et al., 2019) noted that Cronbach's alpha for attending was reported across time (T1, T2, T3) for home (.70, .66, .69), school (.42, .38, .28), and community (.61, .60, .65). This suggests that while the psychometrics of this measure for home and community remain good, the measure for school should be interpreted with caution in this population as it is not measuring a single cohesive concept of school participation. For this reason, the PEM-CY can help with answering, 'How do types and levels of participation at school change over time?' (with the school subscale being interpreted with caution), but the school participation subscale is not reliable enough to use as an outcome variable to answer, 'What aspects of education programs facilitate or hinder participation at school?' or 'What child and family characteristics facilitate or hinder participation at school?'. The poor alpha for the school subscale of the PEM-CY is not reported in studies of participation in other neurodevelopmental disorders, suggesting that the construct of school participation may need to be measured with an autism-specific subscale in the future.

As the PEM-CY school subscale cannot be used as a reliable outcome variable, the research question has been amended to 'How do types and levels of participation at school, at home, and in community change over time?'.

The PEM-CY questionnaire also includes questions related to environmental factors which may influence children's participation. These factors include the physical environment, demands (physical, cognitive, and social) of the activity, and attitudes of others that relate to school (9 items), home (7 items), and community (9 items). To determine the impact of environmental factors on children's participation, parents were asked to rate the helpfulness of environmental factors on a scale of *usually helps/not an issue, sometimes helps, sometimes makes harder,* or *usually makes harder*. Parents were also asked to rate the availability and adequacy of resources to support their child's participation across school (8 items), home (5 items), and community (7 items). Items are rated on a scale of *usually yes/not needed, sometimes yes, sometimes no,* and *usually no.*

2.5.2 Secondary outcome measures

Secondary outcomes included a measure of academic competence (Academic Competence Evaluation Scales [ACES]; DiPerna & Elliot, 2000) which was administered at T2-T6 for each child where the parent consented for school contact and the principal and teacher consented for school participation. The ACES contains 73 questions that assess the academic functioning of students in grades K-12. It measures academic skills (33 items) (reading/language arts, mathematics, critical thinking) and academic enablers (40 items) (interpersonal skills, engagement, motivation, study skills). Teachers rated their student's academic skills in comparison with expectations at the school 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/A option for each question if the teacher has not had the opportunity to observe the skill. For the academic enablers, teachers rated how frequently their student showed 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 from *not important* (1) to *critical* (3). A raw score was obtained for each of the academic skill areas and the academic enablers areas.

The FOS-R (Bailey et al., 2011) consists of two sections and was administered at T1, T3, T5, and T6. Section A consists of 24 items and focuses on the five (5) family outcomes of understanding your child's strengths, needs and abilities; knowing your rights and advocating for services; helping your child develop and learn; having support systems; and accessing the community. Section A assesses the extent to *which* families have achieved these outcomes on a 5-point scale ranging from (1) *not at all* to (5) completely. Section B consists of 17 items and focuses on the three (3) helpfulness indicators of knowing your rights; communicating your child's needs; and helping your child develop and learn. Section B assesses the helpfulness of early intervention on a 5-point scale ranging from (1) *not at all helpful* to (5) *extremely helpful*.

2.5.3 Explanatory factors

To be better able to explain the educational and participation trajectories of children on the autism spectrum in this study, factors that may potentially interact with the outcomes were also examined. These factors were selected based upon a thorough literature review, with the details of each measure provided in Table 1. Family history and measures of child, family, and educational environmental factors were included. The child factors included behavioural and emotional difficulties (as measured by the DBC; Einfeld & Tonge, 1992) completed by the parents and the SDQ (Goodman, 1997) completed by teachers; communication skills (measured by the CCC-2; Bishop, 2006) or Pragmatic Profile of Everyday Language (Dewart & Summers, 1995); adaptive behaviour (measured by the Vineland Adaptive Behaviour Scales; Sparrow et al., 2005); sensory behaviours (SSP-2; Dunn, 2014); and child anxiety (ASC-ASD-P; Rodgers et al., 2016). Parental stress (measured by the PSI-SF-4; Abidin, 2012) and family demographics were also assessed. Educational environment was documented through the teacher and parent surveys. The data collection timeline for each year of the project (T1-T6) is shown in Table 3.

Table 3: Summary of data collection and timeline

Timeline	T1	T2	T3	T4	T5	T6
Parent/Caregiver						
Family history	X	X	X	X	X	X
PEM-CY	X	X	X	X	X	X
SCQ	X			X		
CCC-2	X		X		X	X
VABS-II	X	X	X	X	X	X
PPEC	X					
DBC	X		X		X	X
SSP-2	X		X		X	X
FOS-R	X					
PSI-4 Short	X		X		X	X
ASC-ASD-P		X	X	X	X	X
Principal and Teacher						
Principal survey	X	X	X			
Teacher survey	X	X	X	X	X	X
ACES		X	X	X	X	X
SDQ		X	X	X	X	X

2.6 Data collection and storage

The online questionnaires were developed in the online password protected survey system, Qualtrics. An internet link to the questionnaire was sent to each participant via email and their responses were stored in Qualtrics. Once all the data were collected annually for each of the online questionnaires or at the request of the LASA Research Team members, the Project Coordinator downloaded the data (into either a SPSS or EXCEL file) into a password protected Google Drive folder at Griffith University. The Project Coordinator de-identified the data prior to making the data available to the LASA Research Team.

In 2016 the data was moved from the SalesForce Platform to a Redcap server hosted by in Australia at Griffith University, with all data also being encrypted to meet the updated data storage requirements. All data transfers are encrypted, and security reviews are conducted by the Cybersecurity group at Griffith. Redcap was used to capture contact details, notes, and details and to record communication with the children, parents, school representatives, and other contacts as required, and is only accessible by two members of the LASA Research Team.

2.7 Dissemination

Parents/caregivers, teachers, and principals received general updates about the study through a video each year as well as access to social media pages of the Autism Centre for Excellence. Throughout the study, aggregate results were presented in an accessible format for a lay audience. The Autism Centre for Excellence social media site also kept participants informed about what is new in autism spectrum disorders and evidence-based strategies to use in the home and the classroom. After the final round of data collection, participants were given priority registration to seminars hosted by Griffith University Autism Centre of Excellence in May 2021 showcasing a range of current and completed research projects. There was a seminar tailored to parents/caregivers and one for schools. Both seminars were well attended in person and online and both were recorded for those unable to attend on the day either in person or virtually.

If parents wished to receive formal scored reports for the standardised child assessments included in the questionnaire, they were required to complete a Client Consent to Share Information Form B. This allowed the LASA research team to share the scored reports with the child’s health and/or allied health professional.

2.8 Data analysis

The data collected in the study comprised longitudinal data on participation and trajectories for children on the autism spectrum. However, the study was designed with sample sizes large enough to allow for cross-sectional comparisons (within or between age group) at each time point. Cohort effects for some variables can also be explored by comparing data from when both groups are 9-10 years old (T1 for the 9-10 cohort and T6 for the 4-5 cohort). Missing data have been explored in each cross-sectional paper and will be described and discussed in two final results papers.

To optimise the longitudinal methodology, it is important that the most suitable analysis is applied for each research question. Analysis of data for each published study, including limitations, has been described in each published paper as appropriate.

2.9 Ethical considerations

The study received ethical approval from all participating organisations. All parents provided consent for their child to join the study. Parents also chose whether to consent for teacher and principal questionnaires to be collected. Results from standardised questionnaires were shared with nominated health professionals if this was requested by the caregiver who consented to take part in the study.

We did not anticipate that participants would be subject to any significant risks during this study. If parents/caregivers needed to discuss any elements of the questionnaire they were able to contact the Project Coordinator who directed them to an appropriate member of the clinically trained staff within the team. The research team were willing and able to refer parents to a range of specialised support services if this was deemed necessary or helpful.

All participant information is stored in accordance with the NHMRC best practice. All the questionnaires were completed online, but any personal identifiable information that was sent in (such as copies of diagnostic reports) is stored in a locked filing cabinet. Once downloaded from the online database, all participant data are anonymised by allocating each participant with an ID number. Anonymised participant data are saved on a password-protected secure computer drive to which only members of the research team have access. Identifiable data are stored in a separate location from anonymised participant data.

2.10 Method of the longitudinal study

> Full research paper citation:
> Roberts, J., Adams, D., Heussler, H., Keen, D., Paynter, J., Trembath, D., Westerveld, M., & Williams, K. (2018). Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism. *British Medical Journal-Open, 8*(1), e017082. https://doi.org/10.1136/bmjopen-2017-017082
> Free to access link: Protocol for a prospective longitudinal study investigating the

participation and educational trajectories of Australian students with autism (griffith.edu.au)

Full research paper citation:
Roberts, J. M., Paynter, J., Trembath, D., Westerveld, M., & Williams, K. (2020). Designing a longitudinal study of development of students with autism: Focus on learning, education, and meaningful outcomes. In *SAGE Research Methods Cases.* https://www.doi.org/10.4135/9781529735628

3. Findings

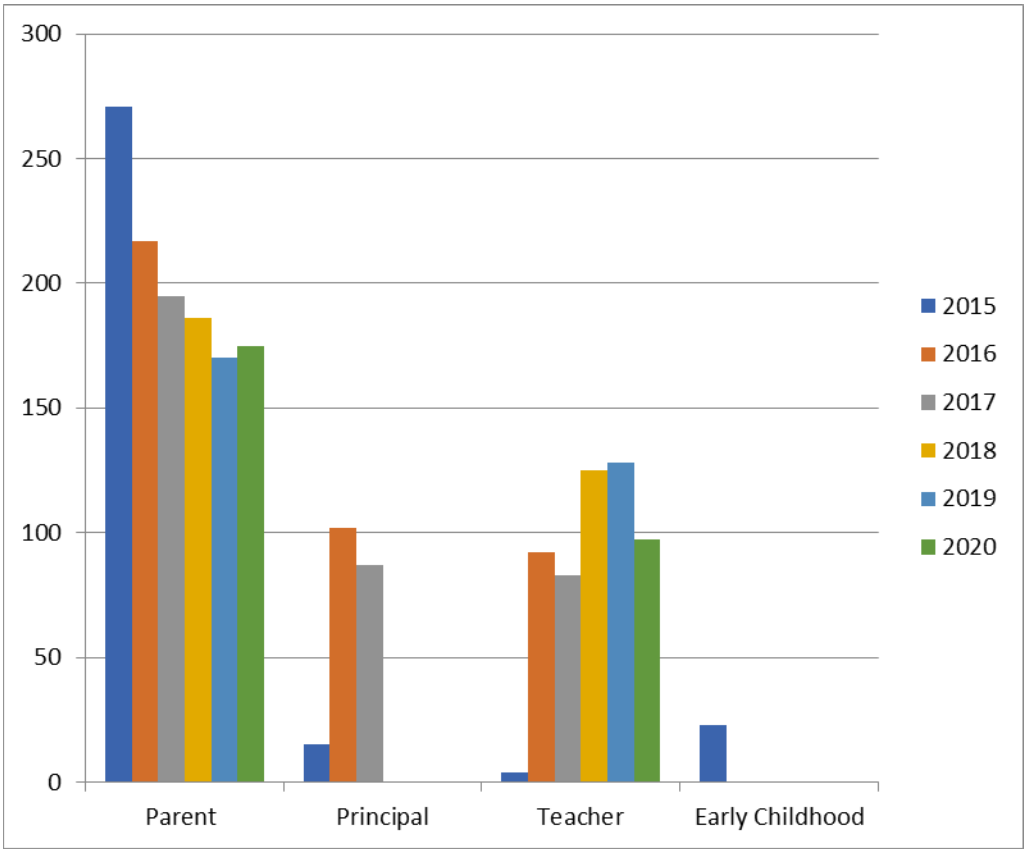
3.1 Participant numbers and retention

Initially, 272 participants were recruited, with one withdrawal during T1, resulting in 271 participants in the first year. The number of participants who remained in the study can be seen in Table 4. All participants who had not withdrawn were invited to participate each year. Retention from T1 to T2 was 80%, T1 to T3 72%, T1 to T4 69%, T1 to T5 63%, and T1 to T6 64%. These statistics potentially help with planning cohort sizes for future longitudinal studies.

Table 4: Completed parent, principal and teacher surveys 2015 – 2020

	2015	2016	2017	2018	2019	2020
Parent	271	217 (80% of T1)	195 (72% of T1)	186 (69% of T1)	170 (63% of T1)	175 (65% of T1)
Principal	15	102	87	-	-	-
Teacher	4	92	83	125	128	97
Early Childhood Teacher	23	-	-	-	-	-

Figure 2: Data collection overview: Parent, principal, and teacher surveys 2015 – 2020



Early childhood teachers were surveyed in the first year of the study where children were in early intervention services and parents gave permission. No early childhood teachers were surveyed after the first year as all of the younger cohort moved on to school. Teacher recruitment was not very active in Year 1, hence negligible numbers for the first year of data collection. As noted above, the Principal Survey was removed after T3 to help recruit higher numbers of schools/teachers by reducing the burden on principals. The impact of this can be seen by the notable increase from 83 teachers in Year 3 to 125 teachers in Year 4. This is important information for future longitudinal studies in schools.

3.2 Research findings from the LASA

The primary aim of the LASA is to document the educational and participation trajectories and outcomes of Australian students on the autism spectrum over a 6-year period. Analysis of some of the other data collected during the course of the study has already been completed and published (see Appendix 1 for a complete list of publications from the LASA to date). Study findings to date have been presented at relevant research conferences, local research symposiums, and seminars for professionals working with children on the autism spectrum and those in educational research.

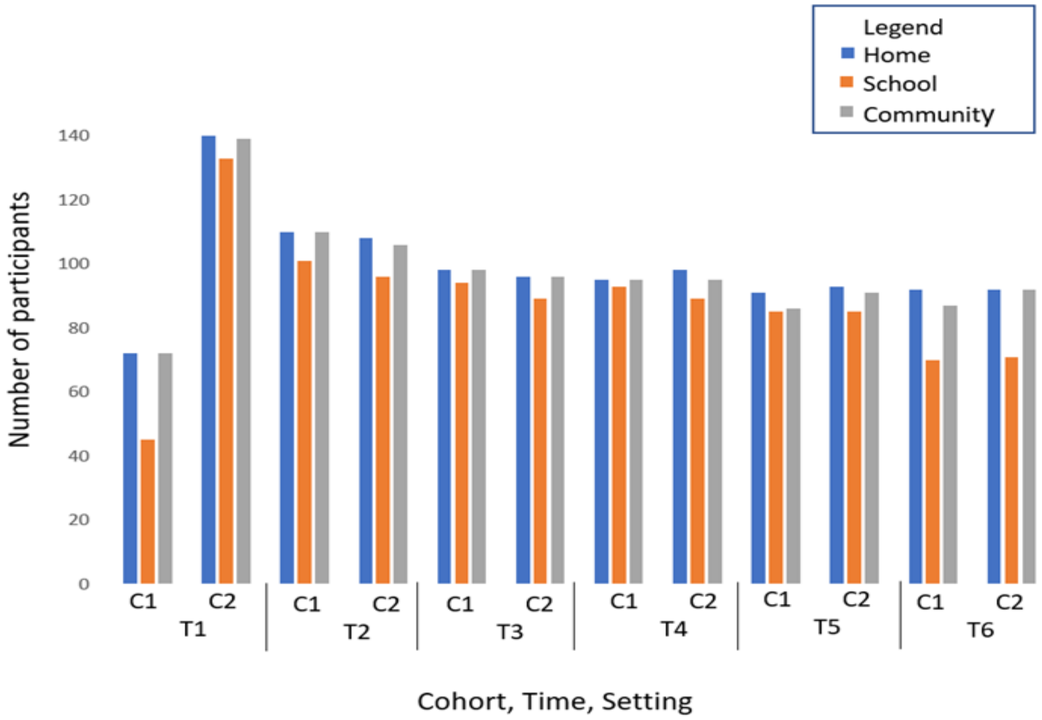
In addition, local stakeholders (such as autism schools and charities) are being consulted about the development of methods for dissemination. Families and schools have been kept up to date with findings by means of annual videos describing the results to date and have been given information about accessing the LASA website where all findings are noted, in addition to lay summaries and links to papers.

Now the longitudinal data set is complete, we will publish the results of the key research questions as well as continuing to publish findings in relation to other research questions in peer-reviewed mainstream and specialist educational journals. The main findings in relation to the educational and participation trajectories and outcomes for Australian students on the autism spectrum over the six annual data points require specialist statistical input and are in the process of being written up for publication. A summary of these unpublished findings is presented below, incorporated with some already published findings.

3.3 Participation trajectories over time

At Time 1, 58 of the 272 participants were below the age level for the questionnaire, explaining why the number of respondents for Time 1 for the younger cohort (Figure 1) is lower than for later time periods. Not all parents completed the measure each year which explains why the number of respondents varies each year (Figure 3), nor did participants always complete the measure for each setting. Some parents may not have felt they had enough information to comment on their child’s participation at school, and a small number of children were home-schooled, both of which may have contributed to the slightly lower response rate on the school setting.

Figure 3: Participant response rate on the PEM-CY across the 6-year period

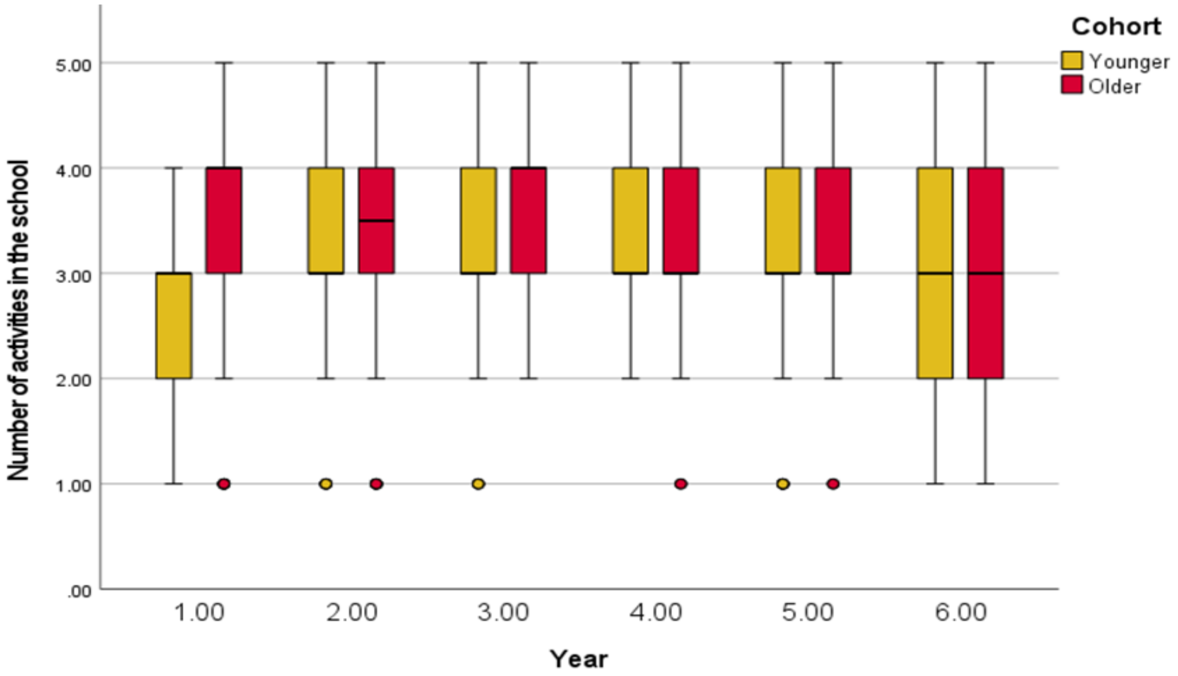


Note.C1 represents younger cohort, C2 represents older cohort.

3.3.1 What are the trajectories of children's participation in school activities?

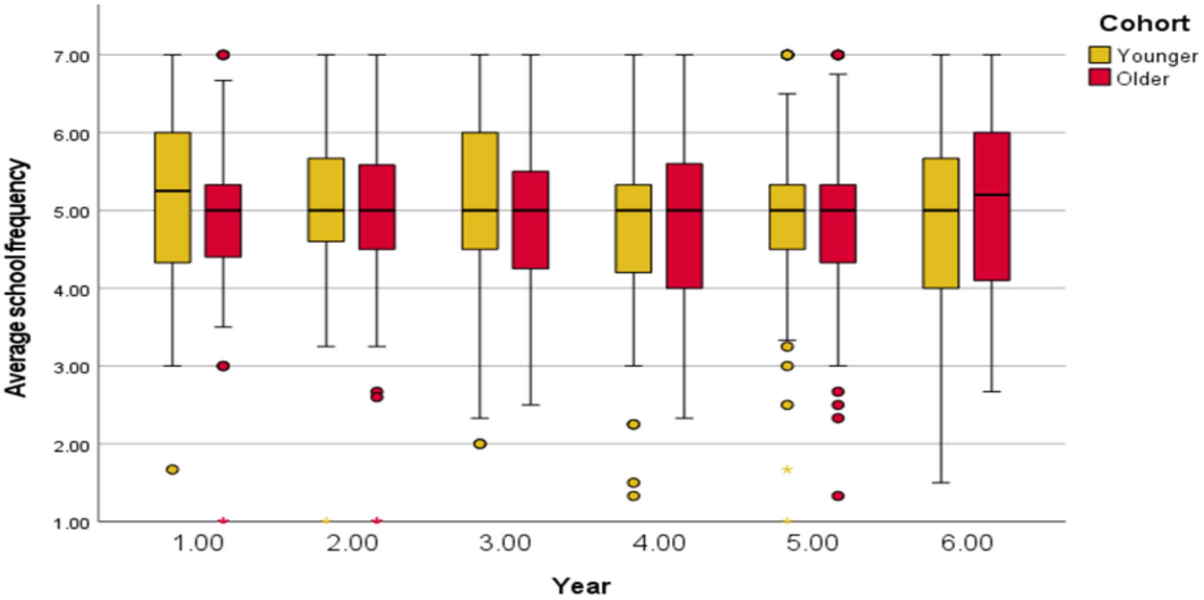
The school subscale asks about five different school activities in which children might participate. The spread of children's attendance for the younger and older cohorts is displayed in Figure 3. In Year 1, children in the younger cohort attended between one and four school activities, with 50% attending two to three activities. In Years 2-5, both the younger and older cohort reported a similar spread in attendance, with 50% of children attending between three and four activities. Both groups reported an increase in the spread of activities in Year 6, with children attending between one and five activities, with 50% attending between two to four activities.

Figure 4: Number of school activities children attended at six time points



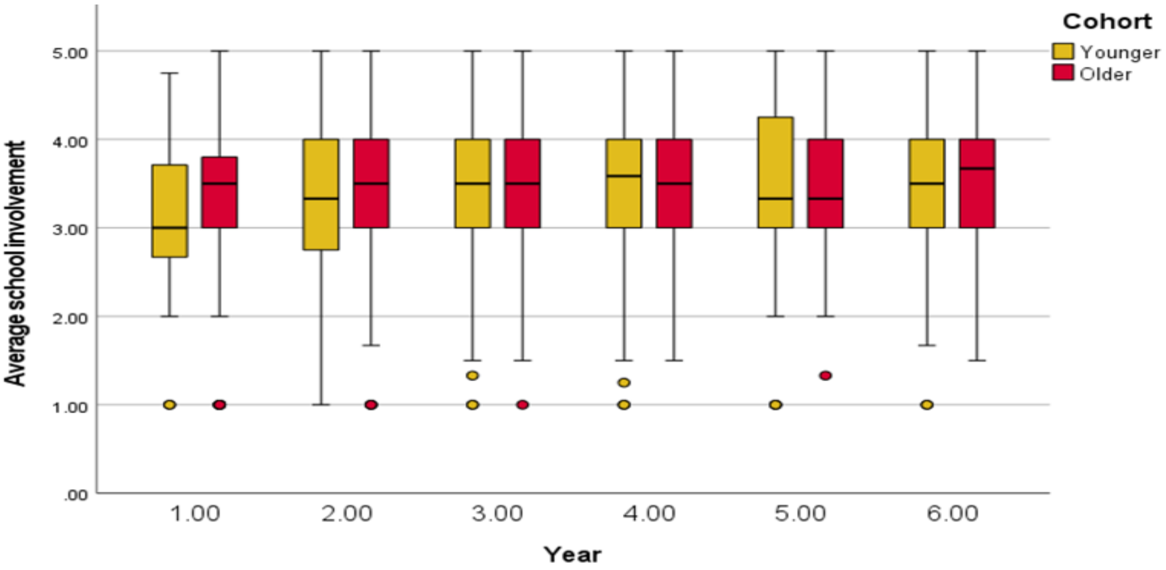
For each of the five items on the school subscale of the PEM-CY, parents are asked to rate how frequently their child participates in this activity at school. It is a non-linear ordinal rating scale; for example, a rating of 2 reflects *a few times in last four months*, a rating of 5 reflecting *once a week*, and a rating of 7 reflecting *daily*. The trajectory of children's frequency of attending school activities across the 6 years of the study is displayed in Figure 5. Frequency of attendance per child is calculated by totalling the attendance ratings for the given items and dividing by the number of items. The wide error bars in Figure 6 highlight the wide variability in how frequently children attend each of the school activities. The trajectory of participation is relatively stable across the study for both cohorts, with the median value being *once a week* (Scale = 5). Caregivers reported at Time 1 that their child attended classroom activities and got together with peers *several times a week* to *daily*, but *rarely* (Median = 0) participated in 'special roles at school' (Simpson et al., 2018). Simpson and colleagues reported that the older children participated in 'field trips and school events' and 'school teams, clubs and organisations' more frequently than the younger children, with the median value reported *a few times in the last 4 months* (Scale = 2) compared to *once in the last 4 months* (Scale = 1) and *never* (Scale = 0) respectively. The low attendance on these three school items was also reported longitudinally by Simpson et al. (2019). Of concern are the outliers in Figure 5 that report median values less than *a few times a month* (Scale = 4). The items on the school scale focus on activities within school organisations and these outliers may be due to the number of participants who were home schooled (3).

Figure 5: Frequency of participation in each school activity at six-time points



For each activity in which the child did take part, parents are asked to rate how involved they felt their child was in that activity. The scale for involvement ranges from *minimally involved* (Scale = 1) to *very involved* (Scale = 5). Again, Figure 6 shows a relatively stable trajectory for both cohorts over time, with 50% of children *somewhat involved* in school activities (Scale = 3) across all time points (Figure 6). At T1, Simpson et al. (2018) reported that both groups had a median score of *somewhat involved* on school items, with the exception of ‘special roles at school’ and ‘school teams, clubs, and organisations’, where the younger cohort were reported to be *minimally involved*. Consistent with the results displayed in Figure 6, the older cohort maintained a fairly consistent pattern of involvement on individual items across T1-T3 (Simpson et al., 2019).

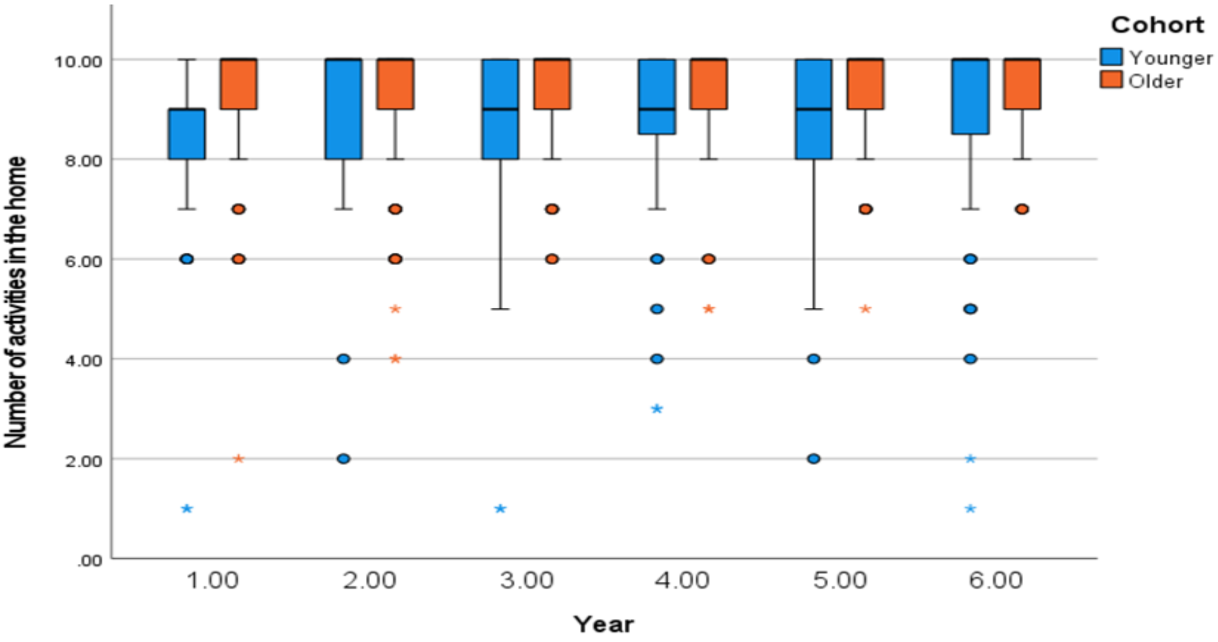
Figure 6. Involvement in school activities children participated in at six time points



3.3.2 What are the trajectories of children’s participation in home activities?

Figure 7 shows the participation of the two cohorts of children on the autism spectrum in home activities across the 6-year period. The trajectory of the number of activities in which children participated in the home setting was relatively flat across the years for the older group, with 50% of the group participating in nine to 10 activities across all years. Although the younger group were reported to participate between a median of nine to 10 activities across the years, as shown by the larger blue boxes and longer error bars on the blue boxes in Figure 7, there was more variability in the number of activities participated in by the younger cohort. For example, in Years 3 and 5 the number of activities the younger cohort participated in at home ranged from five to 10. The outliers in both cohorts would indicate that some children participated in minimal activities in the home context.

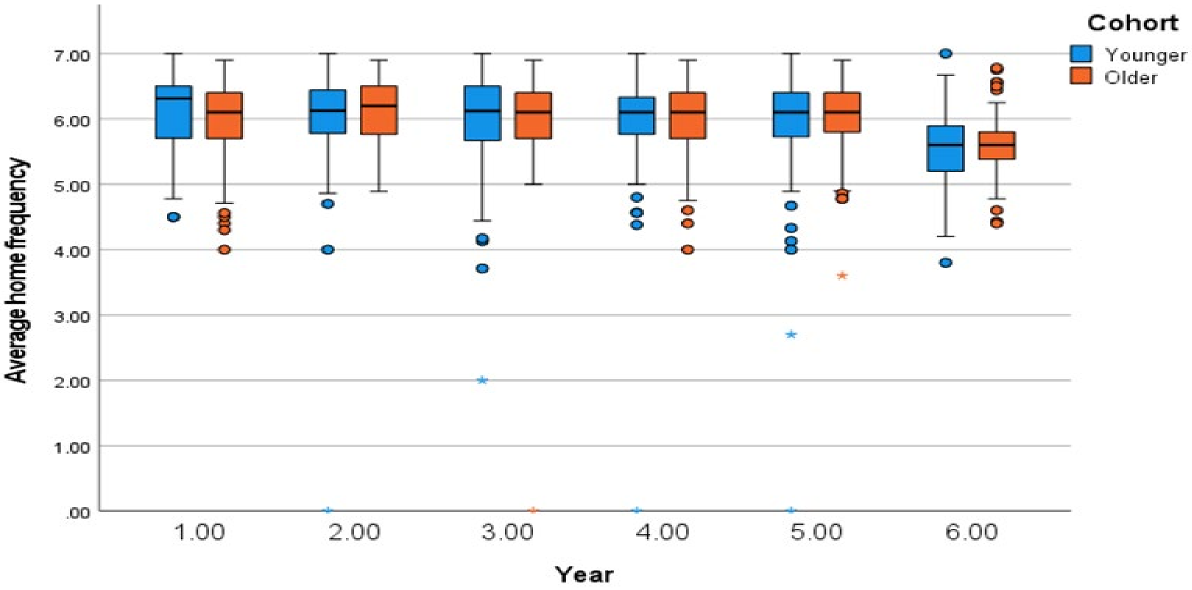
Figure 7. Number of home activities children participated in across the 6-year period



As seen in Figure 8, children in both groups participated in home activities on average a few times a week (Scale = 6) to daily (Scale = 7). Both groups reported a lower median frequency of participation at Year 6. Of note is that Year 6 was 2020, the year when the COVID-19 pandemic began. Although data collection was moved later into 2020 to ensure data were collected post lockdown and post significant restrictions, it is likely that there was an impact on participation.

At T1, the majority of children participated daily in ‘personal care management’, ‘getting together with other people’, ‘watching TV, videos & DVDs’, and ‘computer and video games’ (Simpson et al., 2018). There were differences between groups at item level, with the older group more frequently participating in ‘computer and video games’, ‘household chores’, ‘school preparation’, and ‘homework’ and the younger cohort more frequently participating in ‘indoor play and games’ (Simpson et al., 2018). Simpson et al. (2019) reported a relatively stable pattern of frequency for home activities at item level across T1-T3 which is consistent with the overall pattern displayed in Figure 8.

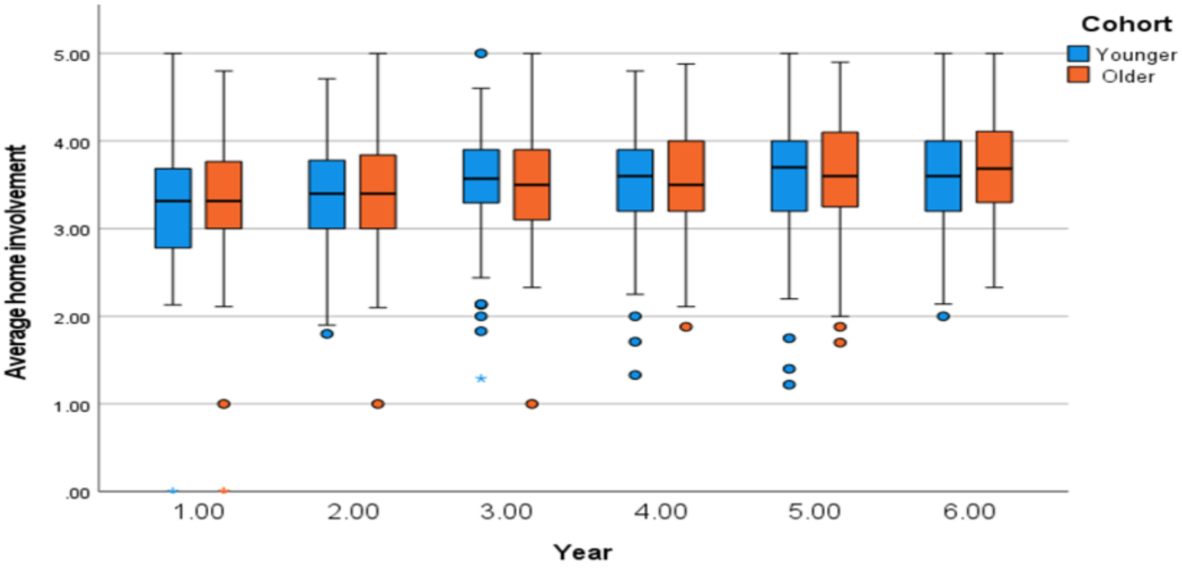
Figure 8. Frequency of involvement in home activities across the 6-year period



Involvement in activities was based on the number of activities the children attended (Figure 9). The median values indicate children in both groups were *somewhat involved* (Scale = 3) in activities, with involvement ranging from *minimally involved* (Scale = 2) to *very involved* (Scale = 5) across the 6-year period. The outliers indicate that there is a group of children who are minimally involved in the home activities they attend.

At item level, children were very involved in 'computer and video games' (Simpson et al., 2018) and this remained consistent for the older cohort T1-T3 (Simpson et al., 2019).

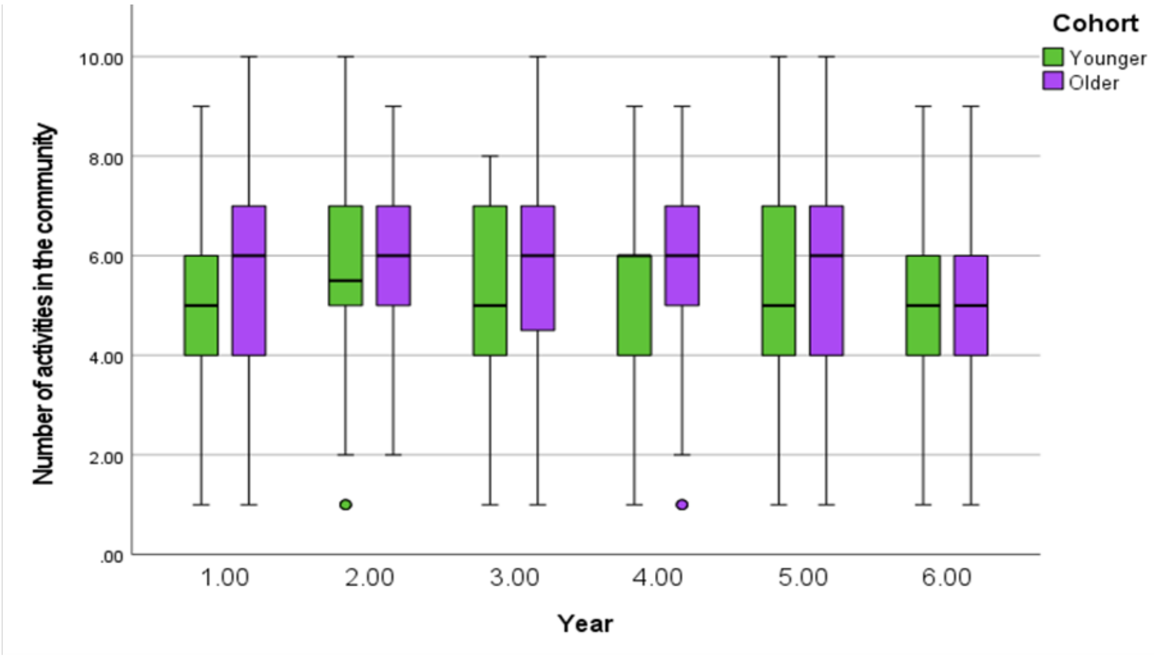
Figure 9. Involvement in home activities across the 6-year period



3.3.3 What are the trajectories of children's participation in community activities?

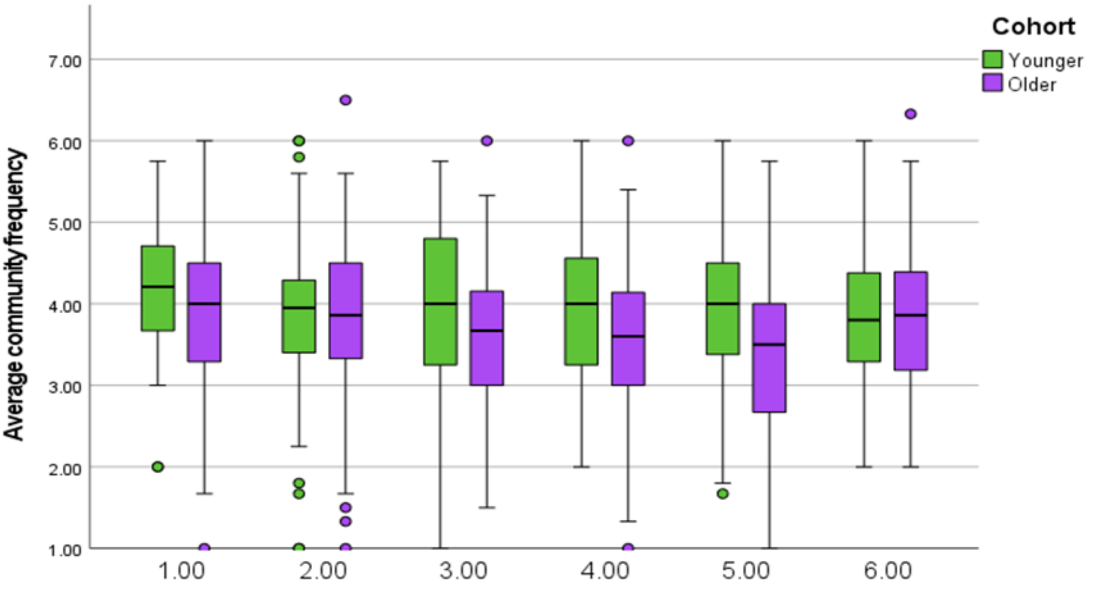
There was a wide distribution in the number of activities children attended in the community (Figure 10) ranging from one to 10. Number of activities attended was higher in the older cohort at Years 1 – 5, with 50% of the older group attending six activities.

Figure 10. Number of community activities children attended at six time points



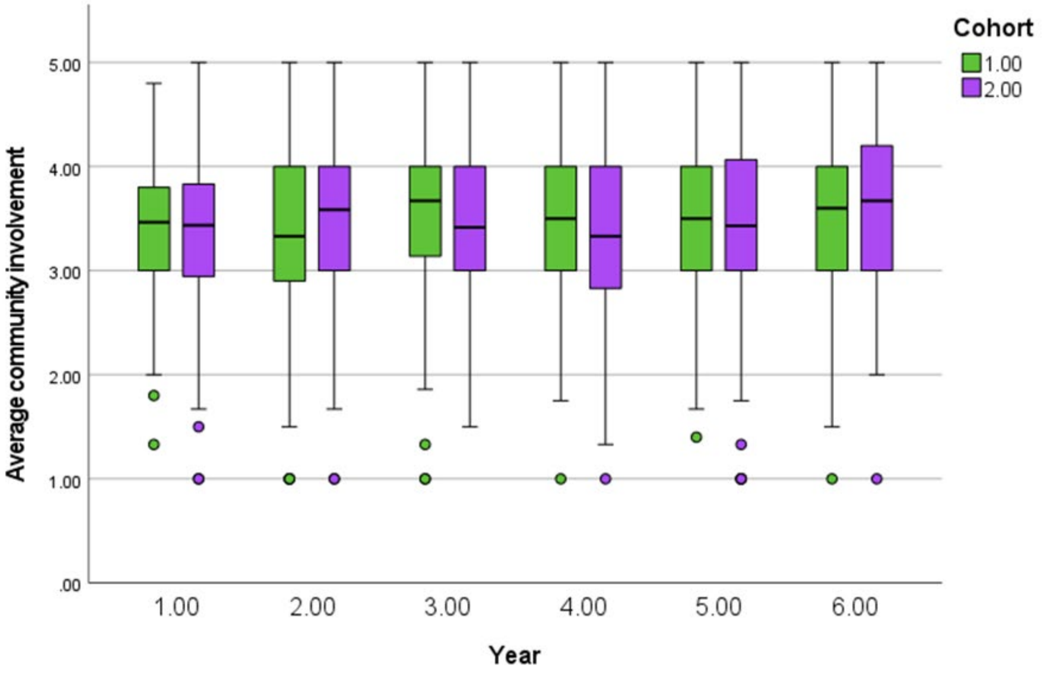
Children's frequency of attendance at community activities ranged from *once in the last four months* (Scale = 1) to *few times a week* (Scale = 6; see Figure 11). The median attendance across the time periods for both groups was centred around a *few times a month* (Scale = 4). At T1, children in both groups rarely attended 'classes and lessons (not school based)', 'organisations, groups, clubs, & volunteer activities', 'religious or spiritual gatherings and activities', or 'working for pay' (Simpson et al., 2018). 'Unstructured physical activities' and 'neighbourhood outings' were identified as the items most attended by both groups, with median values indicating attendance occurred once a week. This pattern of attendance remained consistent for the older cohort across T1-T3 (Simpson et al., 2019).

Figure 11. Frequency of attending community activities at six time points



As displayed in Figure 12, there was a wide distribution in children's reported involvement in activities, ranging from *minimally involved* (Scale = 1) to *very involved* (Scale = 5). The median value was relatively stable across time at *somewhat involved* (Figure 12). At T1, children who attended 'overnight visits or trips' and 'unstructured physical activities' were reported to be most involved in these activities (Simpson et al., 2018). Again, this pattern was consistent for the older cohort across T1-3 (Simpson et al., 2019).

Figure 12. Involvement in community activities at six time points



3.4 Environment-Related Factors

A child's participation in activities can be influenced by personal and environmental factors. Environmental factors include the attitudes of others, the physical environment, and the types of activities and availability of resources. Parent responses were analysed at Year 2, Year 4, and Year 6. The findings from this longitudinal study identify factors which may consistently impact on the participation of children on the autism spectrum across the school age years. This information is important as environmental factors and resources are amenable, and these areas can be targeted to provide more supportive environments to facilitate children's meaningful participation in activities.

3.4.1 Home environment

Parents in both groups rated the physical home environment, relationships with family members, and attitudes of professionals as generally supportive across the three time periods. The cognitive and social demands of the activity were the two items most frequently identified as making participation harder in both groups. More than 60% of parents in the younger and older groups rated both the social and the cognitive demand of the activity as sometimes or usually making participation harder.

The majority (> 80%) of parents reported that resources were adequate or available in the home context to support their child's participation, the only exception being in Year 2, when over 25% of parents in the older group reported 'usually no', they did not have enough money to support their child's participation.

3.4.2 School environment

The social and cognitive demands of the activity were the items most frequently identified as a barrier to school participation. Over 80% of parents in both groups consistently reported that the social demand and the cognitive demand of the activity sometimes or usually made participation in the school environment harder. Nearly 70% of parents in both groups consistently reported the sensory qualities of the school environment and the physical demands of the school activities as sometimes or usually making participation harder. Children's relationship with their peers was also rated by over 60% of parents as a factor that could sometimes or usually make school participation harder. School resources were rated by the majority of parents as usually available and adequate to support their child's participation.

3.4.3 Community environment

Over 40% of parents in both groups reported the physical layout of the environment and the safety of the community as not an issue or usually helping their child's participation. Once again, the social demand of the activity was the most frequently reported barrier to participation in the community, with nearly 90% of parents in both groups identifying this as sometimes or usually making participation harder. Over 80% of parents in both groups identified their child's relationship with peers as a factor that could sometimes or usually make participation harder. Environmental barriers were reported more frequently in the community setting, with attitudes of members of the community, cognitive demands of activities, and the physical demands of activities reported by the majority of parents as sometimes or usually making participation harder.

There was a shift in parents' perception of the lack of programs and services, from over 40% in Year 2, to 30% in Year 4, and 20% in Year 6. Given that there was no difference in parent-reported participation patterns over this period, further investigation is required to determine if there has been an increase in programs and services or if this shift indicates an acceptance of the lack of program and services.

3.5 Summary of participation findings

There are four key findings from this analysis of the PEM-CY data.

1. There is a need for a reliable measure of school participation for students on the autism spectrum. Although the PEM-CY has good Cronbach's alpha scores for other neurodevelopmental conditions, the alpha for the cohort of students on the autism spectrum in the LASA dataset was poor. Future research should aim to co-develop a meaningful measure of participation for students on the spectrum, ideally one that students themselves can self-rate (given the subjectivity of constructs such as involvement).
2. The trajectory of the frequency of participation in school, home, and community activities remains relatively stable over time.
3. Participation is a complex construct and is more than attending an activity. Children's level of involvement in the activities they attended varied from limited to very involved. To further support children, it is important to identify what they consider is meaningful participation.
4. The findings from this study highlight the influence of the environment on a child's participation. In particular, the demands of activities were identified as consistent barriers across settings. Therefore, it is important to consider what activities the child is being asked to participate in and how these activities can be better presented.

3.6 Educational supports and trajectories

Starting in Year 2, each year, caregivers were asked if they consented for the research team to contact their child's school. If parents consented, the child's school was contacted and principals and teachers were invited to complete an online questionnaire. Not all parents consented for the research team to contact the school and not all principals or teachers consented to participate; as a result, the number of teacher respondents is less than the total LASA sample. This also explains why the number of teacher respondents varies each year. The number of teacher respondents each year (Figure 13) and the number of years that teacher questionnaires were received for each participant (Figure 14) are detailed below.

Figure 13. Number of teacher questionnaires received each year of LASA

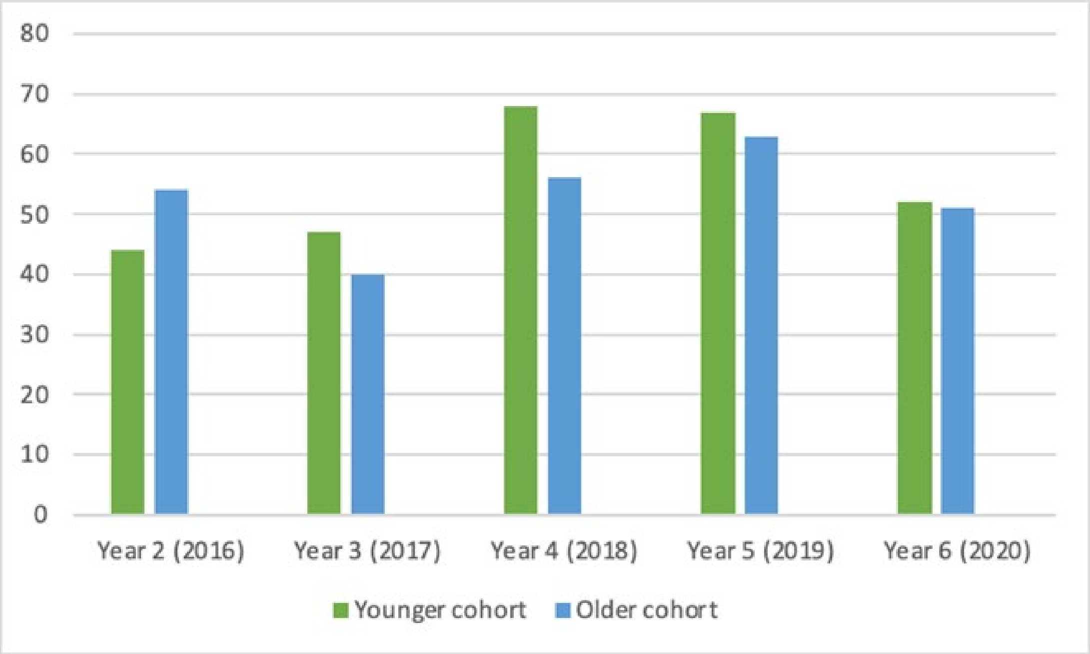
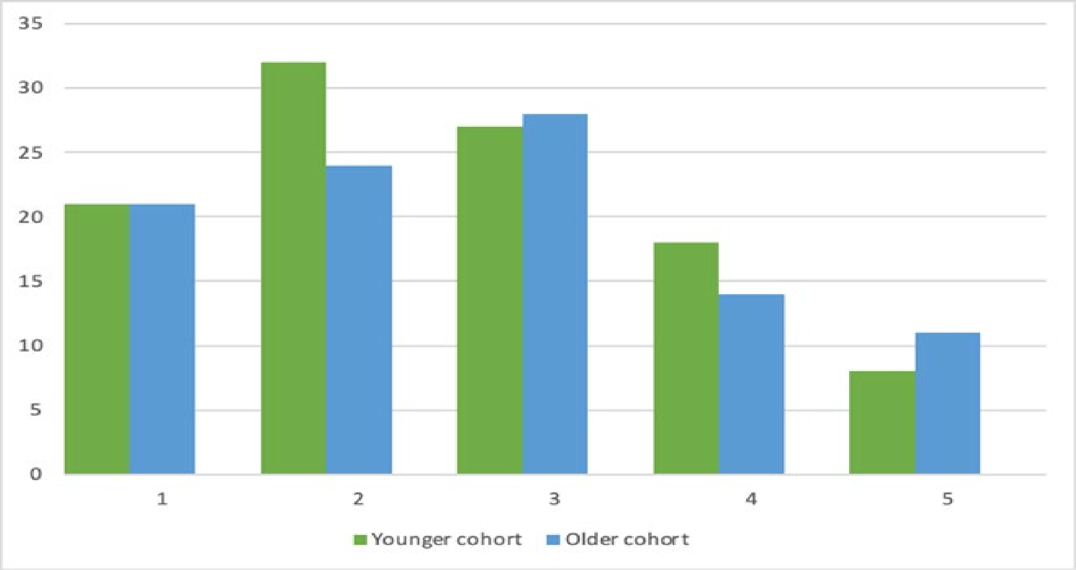


Figure 14. Number of teacher questionnaires received across LASA for each participant (Max 5)



3.6.1 What types of educational programs/interventions do children and their families access?

This has been reported in full in Clark, Adams, Roberts, and Westerveld (2020), where three more detailed questions are addressed:

1. What are the most frequently reported strategies (supports, accommodations, and additional assistance) used by teachers to support the learning of students on the autism spectrum?
2. Do teachers report using these strategies/modifications specifically for the student on the autism spectrum or are they implemented with the same frequency class-wide?
3. Do teachers report differences between students on the autism spectrum and the remainder of the class in (a) student engagement and participation in school activities, and (b) the strategies endorsed as important when evaluating the grades of their students?

Data for this study were provided by 87 classroom teachers educating students from the LASA cohort in Australia, taken from T2 and T3 of the LASA. Of the teachers involved, 61 (70.1%) were teaching in mainstream classes with or without support, 24 (27.5%) were teaching students on the autism spectrum in specialist classes or schools, and for two students, school placement information was not provided. The teachers were predominantly female (*n* = 76; 87.4%). Teaching experience varied across the sample, with the sample spread across total years of experience as a classroom teacher and variable teacher experience of teaching students with disability.

Items in the teacher questionnaire pack were originally developed as part of the National Longitudinal Transition Study-2 and the Longitudinal Study of Australian Children (LSAC; Nicholson & Sanson, 2003). Teachers were firstly asked to tick (yes/no) whether specified supports were provided, because they had a student on the autism spectrum in their class. They were also asked which assessment modifications/adjustments and specified assistance were provided to this specific student on the spectrum within the class setting. Finally, teachers were asked about instructional materials, level of engagement in instructional activities, and factors important in determining grades and evaluating progress in relation to (a) the student on the autism spectrum, and (b) the class as a whole. These three sections of questions were all rated on a 3-point scale, with those asking about instructional materials and level of engagement in instructional activities rated as 0 – *never or rarely*, 1 – *sometimes*, 2 – *often*, and those asking about the importance of specific factors in relation to determining student grades being rated as 0 – *not important*, 1 – *somewhat important*, 2 – *very important*.

Table 5 shows the most frequently reported strategies (supports, accommodations, and additional assistance) used by teachers to support the learning of LASA participants. On average, teachers stated that they were provided with three of the eight classroom supports listed because this student with a diagnosis on the autism spectrum was in their class; that they provided four of the 10 task or assessment adjustments or modifications listed; and four of the 10 classroom support strategies for the student on the spectrum.

Table 5: Summary of supports, accommodations, and additional assistance made available to students on the spectrum (taken from Clark et al., 2020)

Sorted from most to least endorsed by teachers

Supports provided in class due to having child with diagnosis of autism in class		Assessment/task accommodations		Additional assistance provided to student in class	
Information about the student's needs	64 (73%)	Modified test/ Alternative test	65 (74.7%)	Visual support schedules	65 (74.7%)
Teachers' aides/ individual student aides	62 (71.3%)	Slower paced instruction	59 (67.8%)	Teacher aide or personal aide	62 (71.2%)
Consultation with special education staff	41 (47.1%)	Simplified language	51 (58.6%)	Specific learning strategies	46 (52.8%)
PD relating to this student	35 (40.2%)	More time to take tests	47 (54%)	Student progress monitored by special education staff	37 (42.5%)
Special equipment/materials	29 (33.3%)	Additional time to complete assignments	41 (47.1%)	Allied health	35 (40.2%)
Smaller class size	27 (31%)	More frequent feedback	41 (47.1%)	Behaviour support plan	28 (32.1%)
Co-teaching with special education staff	19 (21.8%)	Test read to student	34 (39%)	Self-management training	22 (25.2%)
Support for playground/non-teaching time	18 (20.68%)	Physical adaptations to classroom	32 (36.7%)	Peer tutoring	14 (16%)
None of the above	2 (2.3%)	Shorter or different assignments	29 (33.3%)	Tutoring from another adult	10 (11.5%)
		Modified grading standards	23 (26.4%)	Reader or interpreter	10 (11.5%)

Teachers were asked about which instructional material they used and whether this was specific to supporting the student on the spectrum, or if this was a procedure used for the entire class. There was no significant difference in the instructional material used for those on the spectrum compared to the entire class. For example, use of visual support schedules was high for students on the spectrum (80%) but these were also used as a frequent method of learning support for the whole class (71.8%). The use of communication devices such as the iPad was also reportedly similar for students on the spectrum (24.4%) and the whole class (27.9%). In contrast, when asked how much the student engages in different classroom activities, there were significant differences between engagement levels of the student on the spectrum and the other students in the class. Students on the spectrum were reported to receive more frequent individual instruction from the teacher or another adult, but were reported to less frequently respond to questions, work within a group, work independently, perform or speak in front of the class, or take tests or quizzes. Teachers also reported using different data when determining grades for students on the autism spectrum than for the remainder of the class, noting that they placed less importance on the student's performance relative to a set standard or relative to the rest of the class. They also reported adjusting the requirements for homework for students on the autism spectrum.

This study is an important first step towards understanding the ways in which students on the autism spectrum are supported within their school environments. The findings indicate that while there were no differences in the frequency of use of instructional materials for students on the spectrum compared to their class, there were significant differences in the students' frequency of engagement in these activities as well as significant differences in some of the factors that teachers use to evaluate progress and determine grades.

> Full research paper citation:
> Clark, M. Adams, D., Roberts, J., & Westerveld, M. (2020). How do teachers support their students on the autism spectrum in Australian primary schools? *Journal of Research in Special Educational Needs.* https://doi.org/10.1111/1471-3802.12464
> Free to access link: How do teachers support their students on the autism spectrum in Australian primary schools? (griffith.edu.au)

3.6.2 What are the trajectories of educational outcomes over time?

The LASA teacher questionnaire focussed on collecting information on teacher demographics, the child's academic competences, and their participation and supports at school. The key outcome measure from the teacher data was the Academic Competence Evaluation Scales—Teacher Form (ACES-TF; DiPerna & Elliott, 2000). This is a teacher-rated assessment tool which has 73 items, each of which is rated on a 5-point scale. The scale is completed based on direct observation of a student's skills and behaviours in the classroom setting by respondents who have known the student in their classroom for a recommended minimum of 6 weeks. To help ensure this, the LASA team asked teachers to complete the questionnaire in Term 3 of each year.

There are two sections of this tool which are scored and interpreted differently. Firstly, there are 33 items about academic skills, which include questions on reading, mathematics, and critical thinking such as 'word attack', 'uses numbers to solve daily problems', and 'developing a solution to a problem'. These ask teachers to rate a student's mastery in a particular skill compared to grade expectations, on a 5-point scale ranging from *far below* to *far above* grade level expectation. Secondly, there are 40 items assessing the academic enablers of interpersonal skills, engagement, motivation, and study skills. Example questions for these items are ‘interacts appropriately with other students’, ‘speaks in class when called upon’, ‘persists when task is difficult’, and ‘finishes class work on time’. These are rated on the frequency at which a student shows a particular behaviour, from *never* to *almost always*.

As each subscale has a different number of items, the scores have been calculated as a ‘mean score per item’ so that each subscale score is comparable. Therefore, a subscale score of 3 on the academic competency subscales suggests the cohort is, on average, performing at grade level. An average subscale score of 3 on the academic enabler subscales represents *sometimes*.

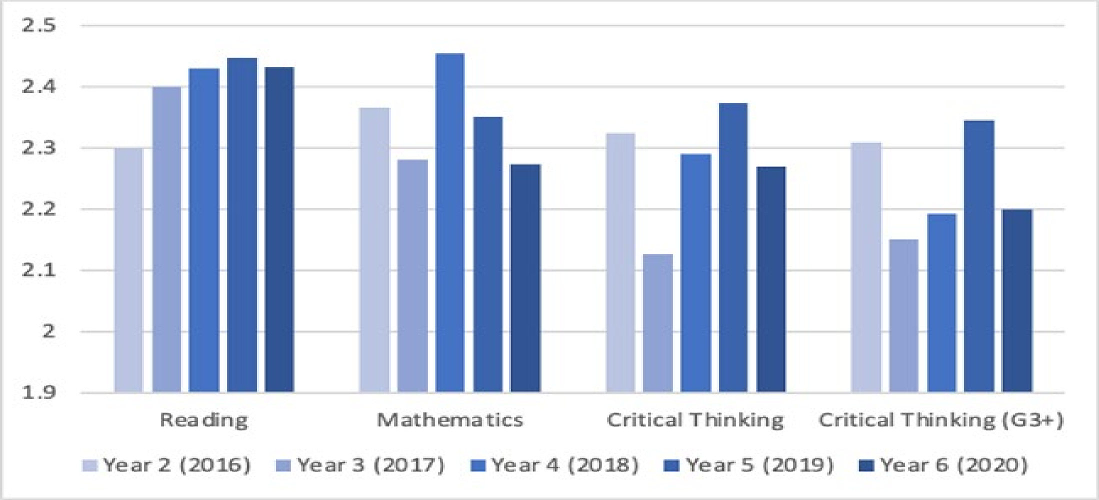
The ACES demonstrates strong psychometric properties for Academic Skills and Academic Enablers. Test reliabilities were .95 and .96, respectively, and interrater agreement .99 and .61, respectively. Mean coefficient alphas for Academic Skills and Academic Enablers scales for the teacher form are .99 (DiPerna & Elliott, 2000). In a paper reporting on T2 and T3 LASA data, Keen et al. (2021) note that Cronbach’s alpha was 1.0 for Reading/Language, .97 for Mathematics, .97 for Critical Thinking, .94 for Interpersonal Skills, .93 for Engagement, .95 for Motivation, and .74 for Study Skills, suggesting that the psychometrics of this measure remained strong for students on the autism spectrum.

To explore educational trajectories over time, the following questions were asked:

3.6.2.1 How are children on the autism spectrum performing academically? Does this differ across subjects or change over time?

Figure 15 shows the performance of children on the autism spectrum on the Reading, Mathematics, and Critical Thinking subscales, as rated by their teachers. The two Critical Thinking subscales reflect the general critical thinking skills and the more advanced skills which would only be expected from Grade 3 and above (G3+). Before interpreting this graph, it is important to note that the number of participants varied each year and, as would be expected, the teacher informants often changed each year. As noted above, a score of 3 would be ‘at grade expectation’ on each subscale.

Figure 15. Mean score per item for entire cohort for ACES subscales across 5 years of LASA data



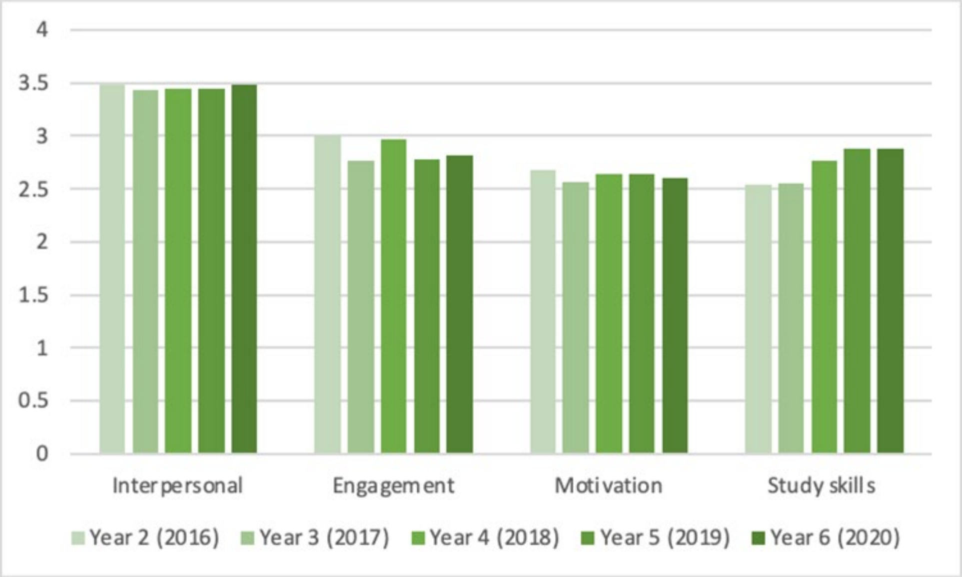
It is important to note that due to the way the ACES is scored (i.e., how the child is performing relative to their peers), a stable score means the group is remaining at the same level compared to their peers while an increase in score means an improvement relative to peers (e.g., often closing the gap with the peers). A score of 3 is ‘at the same level as their peers’ so the closer the score gets to 3, the smaller the gap between the cohort and their peers.

From Figure 15 it is clear that there is considerable variability in the level of skills demonstrated by participants in any one year. We can see that reading shows an upward trajectory over time, suggesting that by Year 5 and 6, the score is closer to grade expectations than in Years 2 and 3. The reading scores tend to be relatively higher than mathematics and critical thinking, suggesting the gap between the autism cohort and their peers is smaller for reading and literacy than for these other skills. The trajectory on mathematics and critical thinking is more complex and will require careful statistical modelling (currently underway).

3.6.2.2 What is the trajectory for children on the autism spectrum in developing academic enablers? Does this differ across areas of academic enablers?

Figure 16 shows the average teacher rating for the cohort of children on the autism spectrum on the academic enabler subscales: Interpersonal Skills, Engagement, Motivation, and Study Skills. Again, as before, the number of students and teachers who completed the questionnaires often differed each year. When interpreting this graph, it is important to note that the number of participants varied each year and, as would be expected, the teacher informants often changed each year. Academic enablers are rated differently from the academic competencies, with the score reflecting how often the student exhibits the behaviour (rating from 1 = *never* to 5 = *almost always*).

Fig. 16 Mean score per item for entire cohort for ACES academic enabler subscales across 5 years of LASA data



Of interest in this graph, we can see that teacher ratings are consistent for each academic enabler, particularly for interpersonal and motivation. Also of interest, and contrary to what may have been expected, is the fact that teachers rated interpersonal skills as the highest academic enabler in each year of the study. Of interest to note is the steady upward trajectory in ratings for study skills over the first 4 years of teacher rating. It is important to note that the number of teacher respondents differed each year (see Table 4) and, as highlighted in Figure 14, few children had data across all timepoints, so the children making up the sample at each year differ.

3.6.3 Do particular child characteristics predict educational outcomes for children?

A cross-sectional study exploring this question was published by Keen, Adams, and Simpson Adams (2021). They used data sets from teachers of 113 children on the spectrum (81.4% males and 18.6% females) who were participants in the LASA. Hierarchical multiple regression analyses were used to identify the predictors for each academic skill. In the initial step, child factors (autism characteristics, child age, receptive language skills, and educational setting) were entered as predictor variables. In the second stage, the three ACES academic enablers (interpersonal skills, engagement, and motivation) were entered into the model to see if these explained any additional variance in academic outcomes over and above the child characteristics.

The results indicate that some but not all child factors predict academic skills. When only child factors were in the regression, child reading/language skills and mathematics were predicted by the child’s receptive language skills and their educational setting, but not their autism characteristics or age. When academic enablers (interpersonal skills, engagement, and motivation) are entered into the regression, different combinations predict the reading/language scores than the mathematics scores. The amount of variance predicted in the reading/language scores was 58%, with unique significant predictors being the child’s receptive language (explained 11% of the variance), their educational setting (mainstream/special, explained 6% of variance), and the child’s motivation (6%). However, for mathematics, the regression explained 52%, with the unique significant predictors being the child’s receptive language (explained 7% of the variance), their educational setting (5%), the child’s motivation (8%), and also the child’s interpersonal skills (6%).

> Full research paper citation:
> Keen, D., Adams, D., & Simpson, K. (2021). Teacher ratings of academic skills and academic enablers of children on the autism spectrum. *International Journal of Inclusive Education*, ePub ahead of print. https://doi.org/10.1080/13603116.2021.1881626

3.7 Summary of educational findings

The data from the LASA have provided important first step towards understanding the ways in which students on the autism spectrum are supported within their school environments and the factors which might support better educational outcomes. The findings indicate that while there were no differences in the frequency of use of instructional materials for students on the spectrum compared to their class, there were significant differences in the students’ frequency of engagement in these activities as well as significant differences in some of the factors that teachers use to evaluate progress and determine grades. Given that student motivation and interpersonal skills can predict 6-8% of a student’s outcome, it is important that teachers are offered additional support to tailor instructional materials to ensure they are motivating and engaging for students on the autism spectrum.

4. Findings from other LASA publications

To date, the LASA has resulted in 23 publications which have been published in high-quality, peer-reviewed journals. Key publications have been summarised briefly below; the full text of each publication can be accessed via the link provided.

4.1 Topic 1: Participation

4.1.1 What do caregivers of children on the autism spectrum report about the frequency and involvement of their children in activities in the home, school, and community?

As part of the annual LASA survey, caregivers completed the PEM-CY reporting on their child's involvement in activities at home, at school, and in the community (both the nature and the frequency of involvement). Distribution frequencies were calculated for each of three time points. Caregivers of 84 participants aged 9-10 years at Year 1 completed the PEM-CY at three annual data collection points. Although participation in the majority of items across home, school, and community remained stable, the longitudinal data suggest that children change the types of socialising activities across time. Over the 3 years there was a decline in physical activity (both organised and unstructured) and in participation in school activities. This decline in participation as children move into adolescence is concerning. Further, reduced participation at this phase of development may potentially limit future participation opportunities throughout adolescence and into adulthood. Further exploration of the participation trajectories of children on the autism spectrum is needed.

> Full research paper citation:
> Simpson, K., Adams, D., Bruck, S., & Keen, D. (2019). Investigating the participation of children on the autism spectrum across home, school and community: A longitudinal study. *Child: Care, Health and Development, 45*(5), 681-687. https://doi.org/10.1111/cch.12679
> Free to access link: Investigating the participation of children on the autism spectrum across home, school, and community: A longitudinal study (griffith.edu.au)

4.1.2 Do caregivers of children on the autism spectrum indicate they desire a change in the frequency with which children do activities and their involvement in activities in the home, school, and community?

Children on the autism spectrum participate less frequently, and in a narrower range of activities, than their non-autistic peers, but little is known about exact participation patterns across contexts or how this is perceived by caregivers. This study aimed to document patterns of participation and caregiver views with regards to frequency and intensity of activities. Caregivers of children on the spectrum aged 5 (*n* = 90) and 9-10 years (*n* = 128) completed the Participation and Environment Measure – Child and Youth (PEM-CY) for home, school, and community. Caregivers reported on frequency of child's participation, level of involvement, and caregivers' desire for change in participation patterns.

Item-level analyses revealed similar patterns of participation across home, school, and community for both cohorts, with some small age-appropriate differences. Caregivers generally desired increased diversity, frequency, and involvement in activities, but a decreased use of electronics (computers, games, TV, and DVDs).

The possibility of autism-specific participation patterns could inform future interventions aimed at enhancing social inclusion. This warrants further investigation through multi-informant designs that seek the perspectives of the child and caregivers.

> Full research paper citation:
> Simpson, K., Keen, D., Adams, D., Alston-Knox, C., & Roberts, J. (2018). Participation of children on the autism spectrum in home, school and community. *Child: Care, Health and Development, 44*, 99-107. https://doi.org/10.1111/cch.12483
> Free to access link: Participation of children on the autism spectrum in home, school, and community (griffith.edu.au)

4.1.3 Does anxiety impact the participation of children and youth on the autism spectrum?

Factors that may impact the participation of children aged 6–13 years on the autism spectrum are explored in this study. Parent-reported data for 131 children with a diagnosis of autism spectrum disorder were examined. The PEM-CY participation measure was used to ascertain the frequency of participation and level of involvement of children in activities in the Home and Community settings. Other measures included in the analyses were VABS receptive language scores, SCQ scores, family income, and anxiety (measured using the ASC-ASD-P, a 24-item questionnaire designed to capture typical and atypical signs of anxiety in children on the autism spectrum). Data were analysed using hierarchical multiple regression analysis.

Anxiety was a unique, significant predictor of the frequency of children's participation (but not involvement in activities) in both Home and Community settings, when controlling for autism characteristics, communication skills, and family income.

Conclusion: Anxiety symptomatology may contribute to the less frequent participation of children on the autism spectrum in home and community activities.

> Full research paper citation:
> Ambrose, K., Simpson, K., & Adams, D. (2021). The impact of anxiety on the participation of children on the autism spectrum. *Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s10803-021-05162-x

4.2 Topic 2: Strengths and positive outcomes

Historically, conditions such as autism have been viewed through a lens of deficit and disability. In more recent times there has been a shift towards considering the strengths as well as the deficits of a condition and also the role of society in defining those deficits. It is likely that special interests (passions) can enable children on the autism spectrum by supporting emotional well-being, promoting learning, and developing vocational skills. To this end, parents were asked to nominate their child's skills and strengths and their special interests in the LASA survey.

In relation to the parent/caregiver experience of their child's strengths and powerful interests, the following research questions were asked:

- What strengths and special interests do parents report?
- Is there a sex difference within the age groups?
- Is there a difference between the age groups?
- Is there a relationship between the reported passions and a reported greatest strength?

Parental reports of their child's strengths and interests from the second year of LASA data collection showed that parents report male and female children demonstrate strengths in academic skills such as reading, spelling, and mathematics. Other skills divided according to gender. Special interests also showed signs of gender preferences, with females being interested in crafts and caring for animals while males were interested in science and engineering. Parents reported tenacity and determination to be a strength, indicating a potential relationship between the special interest and the skill development. There were gender differences in interests between the older and younger groups, as only the older female cohort were interested in technology and sport, and younger males in crafts. Humour and a loving personality emerged as a personality trait of both male and female children. The findings of this study show that parents recognise the value of their child's special interests and abilities. This information contributes to a building body of knowledge that show that special interests and the skills that develop through the tenacity and determination of the child should be considered as having a role in their social, emotional, and educational development.

> Full research paper citation:
> Bruck, S., Clark, T., Roberts, J. (submitted for publication). An emerging appreciation of special interests and strengths of autistic students.

4.3 Topic 3. Sensory

4.3.1 Can sensory subtypes in children and adolescents on the autism spectrum aged 3-15 years, be identified using the item level responses from the Short Sensory Profile-2 (SSP-2)?

Some children on the autism spectrum display sensory differences and have difficulties processing sensory information. Sensory responses displayed may be excessive (hyper) or muted (hypo) and can have a profound impact on a child's life. Hyper and hypo responses have been associated with decreased activity, reduced school and social participation, increased anxiety, challenging behaviours, and poorer cognitive outcomes. The aim of this study was to identify sensory subtypes in children on the autism spectrum using the Short Sensory Profile-2 (SSP-2). Caregivers were asked to rate their children's responses to everyday sensory input by completing the SSP-2 as part of the total caregiver survey. Caregivers rated how often their child showed a behavioural response to everyday sensory input.

First year data from both cohorts (4–11 years, *n* = 271) of the LASA study, that is, parent/caregiver completed SSP-2, were analysed using the Dirichlet process mixture model. A two-cluster model was identified which provided the best solution to subtype sensory responses. Two distinct subtypes were identified: *Uniformly elevated* (67%) with high scores across all quadrants and *Raised avoiding and sensitivity* (33%) with raised scores in the avoiding and sensitivity quadrants. Overall, children showed more frequent responses to sensory input than average and most showed more intense responses to sensory input, which included avoiding sensory input and sensitivity to sensory input. There were no differences between subtypes based on chronological age and autism characteristics measured using the SCQ (total score). In summary, based on the SSP-2, children were reported to experience differences in responses to sensory input, in particular in the area of sensitivity and avoiding.

Through gathering data on sensory measures to explore sensory subtypes, it is also possible to explore item-level profiles which may provide further insight into sensory experiences for individuals on the spectrum. For example, within this sample, over 80% of the group scored *frequent/almost always* on the item ‘is distracted when there is a lot of noise around’. This level of information could inform the creation of ‘autism-considerate’ environments that control some of the factors in the environment that may be challenging for children on the autism spectrum. It is important to understand children’s responses to sensory input to provide supportive environments.

> Full research paper citation:
> Simpson, K., Adams, D., Alston-Knox, C., Heussler, H. S., & Keen, D. (2019). Exploring the sensory profiles of children on the autism spectrum using the Short Sensory Profile-2 (SSP-2). *Journal of Autism and Developmental Disorders, 49*(5), 2069-2079. https://doi.org/http://dx.doi.org/10.1007/s10803-019-03889-2
> Free to access link: Exploring the Sensory Profiles of Children on the Autism Spectrum Using the Short Sensory Profile-2 (SSP-2) (griffith.edu.au)

4.3.2 What is the relationship between sensory subtypes and clinical phenotype including autism symptom severity, cognitive level, adaptive behaviour, attention and withdrawal problems, communication competence, and psychiatric co-morbidities such as anxiety in the Australian Autism Biobank (AAB), the Longitudinal Study of Australian Students with Autism (LASA), and the Autism Subtyping Project (ASP) datasets?

The sensory database from the LASA was combined with data for the Sensory Utilisation grant from Program 1 of the Living with Autism CRC. The Australian Autism Biobank (AAB), the Longitudinal Study of Australian Students with Autism (LASA), and the Autism Subtyping Project (ASP) included the SSP-2 and therefore provides an internationally unique opportunity to understand how sensory modulation differences may manifest throughout early and middle childhood. This project leverages these resources created by the Cooperative Research Centre for Living with Autism (Autism CRC) Early Years Program 1 and School Years Program 2. This project contributes to the research goal of identifying clinically meaningful subtypes of autism, which is a key theme of the Autism CRC research program.

Young people on the autism spectrum were reported to experience higher levels of sensory modulation symptoms and behaviours than normative comparisons. On average, these differences were in the order of two standard deviations above the normative mean. Symptoms associated with sensory hypo-reactivity and seeking did not change significantly over time. Females and males presented overall with similar sensory modulation symptoms. However, females demonstrated heightened responses on six specific sensory behaviours. Cluster analysis identified five interpretable cluster groupings which varied from each other in terms of the severity of their reported difficulties and in their relative focus on sensory hyper-reactivity or seeking behaviours.

The findings of this project on the sensory subtypes help develop tailored interventions that can support individuals who experience distress from different sensory experiences. For example, the sensory subtypes with varying foci in either sensory hyper-reactivity or seeking will be important to recognise in clinical practice. Such ‘personalised’ intervention approaches are crucial in the comprehensive assessment and management as each individual on the spectrum is unique and requires support that is tailored to their life and experience. This principle is a core part of the Autism CRC philosophy, and is also reflected in surveys from around the world that define community research priorities. For example, the recently released consultation report of the Australian Autism Research Council included an important section about how the built environment can be modified to meet the sensory needs of individuals on the spectrum. In this regard, the current findings are a critical step in the direction of increasing the evidence base and knowledge about how service providers and our community can best adapt to meet the sensory needs of those on the spectrum.

4.4 Topic 4: Behaviour

High levels of emotional/behavioural difficulties are frequently reported in children on the autism spectrum. However, there is an extensive range of types and intensity of behaviours included in the concept of behavioural difficulties. Similarly, there is an extensive range of types and intensity of characteristics of autism and contextual factors which could potentially be predictive of certain types of behavioural challenges. This study focused on the 4-5-year-old cohort of the LASA in the first year of the study because, while it has been argued that adaptive behaviour is one of the best indicators of level of functioning in individuals on the autism spectrum, this has not yet been explored in young children on the spectrum. The aim of the study was to explore such behaviours in relation to individual factors. The questions the authors were addressing were:

- To what degree do child and family factors and adaptive functioning predict behavioural and emotional presentation in 4-5-year-old children on the autism spectrum?
- Do these prediction models differ according to the aspect of behavioural and emotional presentation that is being assessed?

Parents of 130 children aged 4–5 on the autism spectrum completed a questionnaire made up of standardised (DBC-P; Einfeld & Tong, 1992) measures of their child's behaviour and adaptive behaviour (VABS-II; Sparrow et al., 2005). The survey also included non-standardised questions about family factors (family income, parent mental health diagnosis) and child factors (age, gender, autism diagnosis, medication status).

Hierarchical multiple regressions explored child and family characteristics in relation to children's emotional/behavioural presentation. The results highlight the predictive relationship between a specific child factor (SCQ score – degree of autism) and family factor (parental mental health diagnosis) and specific aspects of the child's behaviour as measured on different subscales of the DBC-P. Different aspects of the behavioural profile were associated with different factors, with child autism characteristics, medication use, and parent mental health making significant unique contributions to a range of behavioural subscales. The findings did not support the hypothesis that adaptive functioning as measured on the VABS-II would be a significant independent predictor. Understanding individual profiles beyond total scores is therefore needed to truly understand the emotional and behavioural profile of specific subgroups. These findings highlight the critical importance of intervention efforts in the early years to reduce the risk of, or change the course of, emotional and behavioural problem development.

> Full research paper citation:
> Adams, D., Paynter, J. Clark, M., Roberts, J., & Keen, D. (2019). The Developmental Behaviour Checklist (DBC) profile in young children on the autism spectrum: The impact of child and family factors. *Journal of Autism and Developmental Disabilities, 49*, 3426–3439. https://doi.org/10.1007/s10803-019-04067-0
> Free to access link: The Developmental Behaviour Checklist (DBC) Profile in Young Children on the Autism Spectrum: The Impact of Child and Family Factors (griffith.edu.au)

4.5 Topic 5: Anxiety

Anxiety is understood to be a common experience for individuals on the autism spectrum and one of the most common co-occurring diagnoses for children on the autism spectrum. Up to 40% of individuals on the autism spectrum meet criteria for one or more anxiety disorders. However, the nature and impact of anxiety in the autistic population is not yet well understood. There is a need for research into the nature, identification, impact, and management of anxiety in this population.

There is increasing evidence that while some aspects of anxiety are similar in those with and without a diagnosis of autism, there are also some aspects of anxiety which can manifest differently in children on the spectrum. The need for a measure of anxiety in the autistic population has been addressed with the development of an autism-specific anxiety scale, the Anxiety Scale for Children with ASD (ASC-ASD; Rodgers et al., 2016). The measure was adapted from a measure of anxiety designed for typically developing children and recognises the overlap of anxiety experiences between those with and without a diagnosis of autism, as well as measuring additional autism-specific factors not captured on measures designed for typically developing individuals. It may be that health-related quality of life (HRQoL) in particular is impacted by anxiety in children on the autism spectrum. Research is needed to firmly establish the relative contribution of anxiety symptomatology and autism characteristics to the HRQoL. Understanding the impact of anxiety on the physical, social, emotional, and psychological functioning domains of children on the autism spectrum can help to inform appropriate provisions during childhood to minimize maladjustment and to improve well-being during adolescence and adulthood. The use of more reliable, valid, and autism-considerate measures of anxiety will assist with intervention planning and the evaluation of intervention strategies within and across contexts.

While research has found there are high rates of anxiety disorder among individuals on the autism spectrum, much of this research has focused on youth and adults. Most research doesn't consider anxiety in autism until children are aged 8 or over and little is known about early signs of anxiety in young children under the age of 8 years. Yet it does appear that anxiety symptoms manifest early in the life of a child on the autism spectrum, and that age is likely to be a factor in relation to type and severity of anxiety across the lifespan.

4.5.1 What symptoms of anxiety do parents report in their 5-6-year-old children on the autism spectrum?

In this study, anxiety-related symptomatology in LASA participants (*n* = 95) in the 5-6-year-old cohort was measured using the Anxiety Scale for Children with Autism Spectrum Disorder (ASC-

ASD). Of the four subscales comprising the ASC-ASD, the subscale of Uncertainty appeared to be particularly elevated in this group of children. Item 16 in this subscale, *My child always needs to be prepared before things happen,* received the highest score among the 24 items on the measure and only two parents reported an absence of symptoms on the Uncertainty subscale. It is evident that the 5-6-year-old children in this study experience a range of anxiety-related symptoms according to the ASC-ASD, with the most prevalent symptoms relating to uncertainty. Early interventions that focus specifically on ameliorating these symptoms of anxiety may therefore prove particularly effective for this population. Research is needed to identify effective early intervention strategies and to determine if such interventions can protect against the development of anxiety disorder in later childhood, adolescence, and adulthood.

> Full research paper citation:
> Keen, D., Adams, D., Simpson, K., den Houting, J., & Roberts, J. (2019). Anxiety-related symptomatology in young children on the autism spectrum*. Autism: International Journal of Research and Practice, 23*, 350-358. https://doi.org/10.1177/1362361317734692
> Free to access link: Anxiety-related symptomatology in young children on the autism spectrum (griffith.edu.au)

4.5.2 What symptoms of anxiety do parents report in their 10-11-year-old children on the autism spectrum?

This study aimed to use an autism-specific measure (ASC-ASD) to explore the profile of typical and atypical anxiety symptomatology in 10-11-year-old autistic children. In this study, associations of anxiety symptomatology with adaptive behaviour and autistic characteristics were examined, in addition to the level of agreement between ASC-ASD scores and parent-reported anxiety diagnoses.

Using data from the second year of the LASA study, 100 parents of 9-12- year-old autistic children completed the ASC-ASD, Vineland Adaptive Behavior Scales − Second Edition, and Social Communication Questionnaire as part of the annual survey. Results show high rates of anxiety symptomatology, with 63% of parents rating their children in the clinical range. Atypical symptoms of anxiety were endorsed at high frequency. Items from within the Uncertainty subscale were most frequently endorsed, while items within the Anxious Arousal scale were endorsed least often. Children with a parent-reported diagnosis of anxiety disorder scored significantly higher on the ASC-ASD than those without an anxiety diagnosis. This was one of the first studies to explore anxiety symptomatology in autistic children using an autism-specific measure of anxiety. Findings suggest that the ASC-ASD may be a useful tool for the assessment of anxiety symptomatology in autistic children.

> Full research paper citation:
> den Houting, J., Adams, D., Roberts, J., & Keen, D (2018). An exploration of autism-specific and non-autism-specific measures of anxiety symptomatology in school-aged autistic children. *Clinical Psychologist*, 1-12. https://doi.org/10.1111/cp.12174
> Free to access link: Exploring anxiety symptomatology in school-aged autistic children using an autism-specific assessment (griffith.edu.au)

4.5.3 Question asked: 'What do parents notice as the signs of anxiety in their children on the autism spectrum? Are these signs the same at home, at school, or when out in the community?'

In the study, 173 parents of children (6-13 years) in the second year of the LASA we asked to complete survey questions about their observations and interpretations of anxious behaviours in their children and, in particular, the complex interaction between anxiety and autism in different settings.

It was found that over half (52.6%) the parents surveyed felt their child was anxious at home, 77.6% felt they were anxious at school, and 76.2% reported their children were anxious in the community. Parents reported differing presentations of anxiety between settings, with the majority of descriptions relating to observable, behavioural changes (e.g., hides/shuts down, repetitive behaviours) rather than cognitive or physiological signs. Parents also reported using a range of different strategies to manage anxiety across settings. Parents predominantly used proactive strategies to support the management of their child's anxiety across all settings, including routines, practice and predictability, and sensory support adjustments to tasks and expectations. In addition, parents used strategies to aid their child's understanding of the anxiety experience through talking about and explaining the experience. They also worked with their children to develop coping strategies such as relaxation techniques. Contexts and strategies varied, highlighting the need for measuring anxiety in different contexts and trialling interventions in different contexts. There was limited information about anxiety at school, highlighting the need for more work in this area.

> Full research paper citation:
> Adams, D., Young, K., Simpson, K., & Keen, D. (2019). Parent descriptions of the presentation and management of anxiousness in children on the autism spectrum. *Autism: International Journal of Research and Practice, 23*, 980-992.

https://doi.org/10.1177/1362361318794031
Free to access link: Parent descriptions of the presentation and management of anxiousness in children on the autism spectrum (griffith.edu.au)

4.5.4 What impact is anxiety having on autistic children?

For this study, a subgroup of children whose parents were participating in the LASA were recruited. Additional face-to-face direct assessment of anxiety in order to explore the impact of anxiety symptoms in depth was also undertaken.

The Child Anxiety Life Interference Scale (CALIS) and Spence Children's Anxiety Scale (SCAS) were administered to 30 autistic children and their parents. Children and parents reported high levels of anxiety-related life impact across all life domains assessed. Parents reported higher levels of impact than children. Both parents and children indicated that school performance is the life domain most impacted by anxiety symptoms. Findings indicate that anxiety symptoms have considerable negative consequences for autistic children and their parents. Further research exploring the impact of anxiety symptomatology in this population is required.

Full research paper citation:
den Houting, J., Adams, D., Roberts, J. & Keen, D. (2020). Investigating the impact of anxious symptomatology in autistic children. *International Journal of Disability, Development and Education*.
Free to access link: Brief Report: Investigating the Impact of Anxious Symptomatology in Autistic Children (griffith.edu.au)

4.5.5 What signs of anxiety do teachers recognise in their students on the autism spectrum?

While there is a paucity of research into the experience of anxiety at school for children on the autism spectrum, it is well documented that anxiety can have a serious impact on the school experience of children without autism, being associated with poor academic achievement, poorer adaptive outcomes, increased school refusal, and reduced engagement and attainment in both academic and social aspects of school life. We know little about the anxiety of students on the autism spectrum in school contexts. As a result, there is limited detailed information for teachers or educators about how anxiety may present and be managed in the school setting for children on the autism spectrum. As part of the annual teacher questionnaire, teachers completed the School

Anxiety scale – teacher report (SAS-TR) in addition to questions designed to provide a profile of the student on the autism spectrum.

Data were examined to determine whether scores on the SAS-TR differed with child variables or enrolment in a mainstream or special school. Teachers of 92 children aged 5–12 completed a questionnaire pack including the SAS-TR. Elevated levels of anxiety (above the SAS-TR total anxiety clinical cut-off) were noted in 21.7% of the sample, with a larger proportion of children scoring above the generalised anxiety cut-off (27.2%) than the social anxiety cut-off (14.1%). Older participants and those attending mainstream schools had significantly higher scores on the generalised, but not the social, anxiety subscales, with effect sizes suggesting a medium effect.

Parent-completed anxiety measures (ASC_ASD-P) were available for 79 children in the cohort, which enabled examination of the level of agreement between teacher-reported and parent-reported anxiety symptoms. This was found to be weak; however, these findings should be interpreted with caution as the two anxiety measures – ASC-ASD-P and SAS-TR – are made up of predominantly different items, meaning the measures are not really comparable. This speaks to the need for measures with comparable multi-informant versions to gather reliable data on similarities and differences across settings and contexts. The results highlight the need for further, more detailed research into the presentation and impact of school anxiety in children on the autism spectrum attending both mainstream and special schools.

> Full research paper citation:
> Adams, D., Simpson, K., & Keen, D. (2018). School-related anxiety symptomatology in a non-clinical sample of primary-school aged on the autism spectrum. *Journal of School Psychology, 70*, 64-73. https://doi.org/10.1016/j.jsp.2018.07.003
> Free to access link: School-related anxiety symptomatology in a community sample of primary-school-aged children on the autism spectrum (griffith.edu.au)

4.5.6 Does anxiety look the same in boys and girls on the autism spectrum?

It is now recognised that children on the autism spectrum frequently experience co-occurring anxiety. Although a child's sex is thought to impact the prevalence of anxiety in typically developing children, the relationship between sex and anxiety symptoms has not previously been established in children on the autism spectrum.

In this study, the parent-reported anxiety symptoms of male and female children (aged 9–12 years) on the autism spectrum are compared; 24 male and 24 female children with a diagnosis of autism spectrum disorder were matched on age, VABS receptive language scores, and SCQ scores.

Anxiety was measured using the ASC-ASD-P, a 24-item questionnaire designed to capture typical and atypical signs of anxiety in children on the autism spectrum. A combination of descriptive and inferential analyses was used to compare the total anxiety scores, anxiety subscale scores, and anxiety item scores of males and females.

No significant differences were found between the total anxiety scores of males and females, or the Performance Anxiety, Separation Anxiety, or Uncertainty subscale scores. Females had significantly higher anxiety scores on the Anxious Arousal subscale which was due to significant differences on two individual anxiety items within that subscale. Overall, male and female children on the autism spectrum, aged 9–12 years, had similar anxiety scores. The profiles of anxiety in male and female children on the autism spectrum may differ from those reported in typically developing children, warranting further investigation.

> Full research paper citation:
> Ambrose, K., Adams, D., Simpson, K., & Keen, D. (2020). Exploring gender profiles in anxiety symptoms in children on the autism spectrum. *Research in Autism Spectrum Disorders*. https://doi.org/10.1016/j.rasd.2020.101601
> Free to access link: Exploring profiles of anxiety symptoms in male and female children on the autism spectrum (griffith.edu.au)

4.6 Topic 6: Family and parent outcomes

Families and teachers are the primary informants for the LASA study. Consistent with a holistic approach to the child and their context, the characteristics and welfare of caregivers is a primary focus for the LASA. Early childhood intervention (ECI) services for children on the autism spectrum commonly espouse a family-centred approach, but outcomes studies often focus solely upon the child, and family outcomes of ECI for autism spectrum disorder (ASD) have received limited research attention to date. Shifting the focus to include and consider parent/family variables as meaningful outcomes of ECI may enhance outcomes for children, parents, and families holistically. The Family Outcomes Survey (FOS; Bailey et al., 2006) has emerged as a potential measure of family outcomes for children with disabilities that may be utilised to address this lack in knowledge and was included in the LASA caregiver survey.

Nb – Early Childhood Intervention explored here was any supports (e.g. Speech Language Pathology, Occupational Therapy, Play Therapy) received before the onset of school. Some parents may have accessed home-based supports or centre-based supports, some part-time and some full-time. The focus here was not on a specific therapy nor on the child. The focus is on how any supports accessed support family-based outcomes.

4.6.1 What is the experience of ECI services for parents of young children on the autism spectrum in relation to access and outcomes?

In the first year of the study, mothers of 96 children on the spectrum (aged 4-5 years) completed a measure of access to ECI and the Family Outcomes Survey-Revised. Family outcomes after ECI were generally positive, although a notable proportion of mothers rated that their child still did not participate in social, recreational, or religious activities that they would want to (15.6%) and that as parents, they did not know about post-ECI options (14.6%). Family outcomes and perceived helpfulness of ECI did not differ with demographic data, with the exception of Accessing the Community subscale, which was significantly higher in families on higher incomes.

> Full research paper citation:
> Adams, D., Keen, D., Heussler, H., Wicks, R., & Roberts, J. (2019). Family outcomes for families of 4-5-year-old children on the autism spectrum who have received early childhood intervention in Australia. *Infants & Young Children, 32*, 186-200. doi: 10.1097/IYC.0000000000000143
> Free to access link: Family Outcomes for Families of 4-5-Year-Old Children on the Autism Spectrum Who Have Received Early Childhood Intervention in Australia (griffith.edu.au)

4.6.2 Do child, parent or family factors predict FOS-R family outcomes and the perceived helpfulness of ECI?

The importance of considering family factors in evaluating the outcomes of early intervention for children on the autism spectrum is established in the following paper. In this study, potential predictors of family outcomes and ECI perceived helpfulness are explored in relation to the Family Outcomes Survey–Revised.

Participants were 97 mothers of children aged 4 to 5 years (*M* = 60.47 months; *SD* = 6.62; 87.6% male) participating in the LASA. Parent and family factors were significant predictors, whereas child characteristics were largely nonsignificant beyond the variance explained by parent and family factors. The findings highlight the importance of parent and family factors when considering family outcomes of ECI and whether parents perceive benefits from their engagement with ECI services. Overall, a shift in the focus of ECI outcome evaluation is indicated, which views parents and families as meaningful to overall optimal ECI outcomes.

Full research paper citation:
Wicks, R., Paynter, J., & Adams, D. (2021). Exploring the predictors of family outcomes of early intervention for children on the autism spectrum: An Australian cohort study. *Journal of Early Intervention*, *43*(1), 3-23. https://doi.org/10.1177/1053815119883413

5. Discussion

In relation to the process and procedures for this longitudinal study, several lessons have been learnt. A clear methodological priority was the retention of participants over the 6 years of the study and the completion by parents and teachers of long online surveys. It can be seen in the graph in Figure 2 that after a sharp drop in numbers over the first year of data collection from parents, numbers completing surveys remained relatively stable; in fact, there was a slight increase in participation in the final year of the study. This may have been because families had more time during the pandemic years and/or were motivated because it was the final year of the study and additional resources were expended to encourage them to complete the final survey. Teacher completion numbers were also quite stable. The number of completions in the final year by teachers is remarkable considering there was disruption to schooling across all states due to the pandemic, particularly in Victoria where teachers were not surveyed at all in 2020 because Victorian schools had been closed for so much of the year. There are several possible reasons for the strong retention of participants in this study:

- There was consistent coordination from a full-time Project Coordinator who was always available to communicate with research participants.
- The Project Coordinator built relationships with participants over the course of the study, was available to listen to parents' concerns and when appropriate refer participants to other research team members qualified and able to give professional advice.
- The Project Coordinator stayed in touch with research participants for the duration of the study to keep them engaged.
- A brief, accessible, annual video was made and provided to participants advising them about the progress of the research and the results of their contribution.
- The momentum of the research team was maintained by having regular monthly team meetings in person and online.

Answers to the original research questions posed at the start of the study are emerging as the analysis of the complete LASA data set progresses. The data collection was completed at the end of 2020 (delayed due to the pandemic) and descriptive analysis of changes in the type and level of participation at school over time for the participants is currently underway.

How do types and levels of participation at school change over time?

As part of the annual LASA survey, caregivers of children in the LASA study completed the PEM-CY reporting on their child's involvement in activities at home, at school, and in the community (both the nature and the frequency of involvement). Although participation in the majority of items across home, school, and community remained stable, the longitudinal data for the older cohort for the first 3 years of the study suggest that children change the types of socialising activities across time. Physical activity and participation in school activities declined. This decline in participation as children move into adolescence is concerning. Further, reduced participation at this phase of development may potentially limit future participation opportunities throughout adolescence and into adulthood. Further exploration of the participation trajectories of children on the autism spectrum is needed. Once profiles have been described, we can then look at factors which differ between children with different profiles and present findings in relation to child and family characteristics that facilitate or hinder participation in school, including further answers to the question:

What aspects of education programs facilitate or hinder participation at school?

In relation to parent ratings of participation at school, while the psychometrics of the parent reported PEM-CY scores for home and community remain good, the measure for school should be interpreted with caution in this population. There was a high degree of variability in ratings of attendance, with attendance highest in TI for the older group and in T6 for both groups. Children attended on average fewer activities than would be expected. Their average involvement was 'somewhat involved'.

Analysis is ongoing to determine:

- What child and family characteristics facilitate or hinder participation at school? and
- Does type and level of child participation in educational programs predict educational outcomes over time?

In relation to participation at home, both groups were reported by parents to participate in nine of the 10 activities rated a few times a week. There was more variation in the younger group and participation for both groups dropped off in Year 6. It is possible that this was related to the global pandemic in 2020 which was the final year of data collection. Survey questions about the pandemic and its effects on children and families were included in the final Year 6 survey for parents and data are currently being written up for publication. Involvement in home activities rated by parents was consistent for both groups across the 6-year data collection period with an average rating of ‘somewhat involved’.

In relation to participation in community activities, the older group attended more community activities than the younger group, with both groups understandably attending fewer community activities in Year 6 (2020). As for school, the average involvement was reported by parents to be ‘somewhat involved’ for both groups.

A study of the data relating to the impact of anxiety on participation indicated that anxiety symptomatology may contribute to the less frequent participation of children on the autism spectrum in home and community activities.

In conclusion, analyses revealed similar patterns of participation across home, school, and community for both cohorts, with some small age-appropriate differences. Caregivers generally desired increased diversity, frequency, and involvement in activities but a decreased use of electronics (computers, games, TV, and DVDs). The possibility of autism-specific participation patterns and the cross-sectional study by a PhD candidate suggest the role of anxiety could inform future interventions aimed at enhancing social inclusion. This warrants further investigation through multi-informant designs that seek the perspectives of both the child and their caregivers.

In relation to education, descriptive data from teachers are being analysed to determine:

- What types of educational programs/interventions do children and their families’ access?

Teachers reported that the supports, accommodations, and additional assistance provided to students on the autism spectrum were similar to those provided for all students, except for the methods of determining grades, which were different for students on the autism spectrum.

In addition, statistical analysis is being done to determine:

- What program elements predict better educational outcomes over time?

Preliminary consideration of the data indicates that there is considerable variability in the level of academic skills demonstrated by participants in any one year. While children may be making gains, this may not always mean they are improving in line with the grade expectations each year. Interestingly, we can see that reading and literacy is the area of highest performance for students on the autism spectrum, while other domains, including critical thinking, are highly variable. In the domains where students on the autism spectrum perform best, they still consistently perform below the expected level for their grade.

Academic enablers (interpersonal skills, engagement, motivation, study skills) were also rated by teachers. Of note, teacher ratings were consistent across years of data collection for each enabler, with interpersonal skills rated highest each year, although this relatively high rating did not translate to high ratings for motivation and engagement. These are preliminary findings, with analysis of data in relation to the types of educational programs that families access and the program elements which predict better educational outcomes over time, yet to be completed. This work is ongoing.

In consideration of the research question:

- Do ASD subtypes (identified in program 1.3) predict educational outcomes for children over time?

Cluster analysis of the combined sensory (Short Sensory Profile – 2; SSP-2) database from the Australian Autism Biobank (AAB), the Longitudinal Study of Australian Students with Autism (LASA), and the Autism Subtyping Project (ASP) identified five interpretable cluster groupings which varied from each other in terms of the severity of their reported sensory difficulties and in their relative focus on sensory hyper-reactivity or seeking behaviours. Sensory modulation characteristics associated with sensory hyper-reactivity peaked in the primary school age group (6-12 years) and remained elevated through adolescence. Data will be analysed to determine whether membership of autism subtypes for LASA participants, as described in this study, predicts their educational outcomes over time.

5.1 Child Characteristics

Some information about child characteristics (summarised here) for some years has been analysed and published. In relation child characteristics, and specifically child behaviour as measured with the Developmental Behaviour Checklist in Year 1 in the 4-5-year cohort, it was found that the degree of child autism as measured by the SCQ, child medication use, and family mental health predicted scores on specific subscales of the DBC but not scores on The Vineland (adaptive behaviour), which suggests some subscales of the DBC are more sensitive to characteristics of autism than the Vineland.

In relation to child sensory characteristics, analysis of Year 1 data from the Short Sensory Profile for both cohorts showed that the majority of children (67%) had uniformly elevated scores across all sensory domains, while one third had raised avoiding and sensitivity scores. This gives us important information to consider when planning intervention and management, particularly modification of the environment to make it more autism friendly.

5.1.1 Do particular child characteristics (language, social, cognitive, or behavioural) predict educational outcomes for children over time?

The review by Keen et al. (2016) shows that academic enablers predict academic outcomes to a greater extent than characteristics of autism.

Two key findings from Keen et al. (2021) in relation to predicting academic outcomes also address this question. Firstly, Keen et al (2021) found that receptive language and educational setting predicted scores on language/reading and mathematics, and receptive language predicted critical thinking skills over and above autism characteristics or child age. Secondly, they found that academic enablers are also important in predicting academic outcomes. The child's interpersonal skills and motivation predicted their critical thinking skills, a child's receptive language, educational setting, interpersonal skills and motivation predicted mathematics ability and a child's receptive language, educational setting, and motivation predicted their reading/language skills

In addition, the current analysis of the longitudinal data will further address this question. Consideration of child characteristics and their relationship to educational outcomes over time continues now the data set is complete.

5.2 Family and parent outcomes

A holistic approach to individuals on the autism spectrum necessitates consideration of family and parent outcomes. Family capacity is likely to have a direct impact on child outcomes and survey components included questions for families and measures of family stress and Quality of Life (QoL). Analysis of data showed that parent and family factors were the most significant predictors of EI outcomes. In another paper, families reported positive outcomes of early intervention for their child although some reported they would like their child to participate more in social, recreational, and religious activities and others reported not knowing about future options for their child.

5.3 Methodological considerations and limitations

5.3.1 Questionnaire data

The format of this study (data collection through questionnaires) allows for a large sample of children and families. However, it is acknowledged that almost all of the information for this study was collected through questionnaires and interviews, without ever meeting the child or family. Exceptions include some direct assessment of subgroups of child participants at specific time points by members of the research team. Because of the overall data collection via questionnaire, it is not possible for the data to include comprehensive direct measures of ability (such as IQ) or formal assessments of autism (such as the ADOS). To address this issue, all parents completed a validated autism diagnostic questionnaire (Social Communication Questionnaire) and were required to send in copies of their child's diagnostic reports.

5.3.2 Bias in recruitment

The nature of the present study required a significant commitment from participants and, where applicable, their teachers and principals. Parents were asked to complete six questionnaires, four of which took approximately two hours to complete. This may have influenced the recruitment procedure and may, over the duration of the study, have reduced completion rates. It is therefore possible that we recruited a biased sample (i.e., families who can afford the time and energy to complete the questionnaire). It may also be that research may only attract parents who have an interest in the focus of this study. To address this issue, efforts were 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 could complete the questionnaire in smaller sections across one month if required.

5.3.3 International pandemic

The outbreak of Covid-19 had an impact on the final data collection in particular. Data collection time periods were extended for some parent/caregiver groups such as parents/caregivers in Victoria and were abandoned completely for Victorian schools as schools were closed for most of the final year of data collection and teachers were unable to comment on their students' participation in school. The impact of the pandemic on the families, schools, and communities in relation to the data being collected has been published in Simpson and Adams (2022).

5.3.4 Importance of including child voice

While a subset of children in the LASA were assessed directly at one time point for specific measures of academic achievement and anxiety, the failure to include the voice of children on the autism spectrum in this project more extensively is a significant limitation. Future research should ensure that capturing the voice of people on the autism spectrum is central to the research design.

In conclusion, this study makes an important contribution to the very limited longitudinal data on the pattern and effects of participation in children on the autism spectrum. Much remains to be done in relation to analysing the data and writing up the findings; however, publications to date provide descriptions of progress and change for children and young people on the autism spectrum. For example, study results are already informing clinicians, children, and their families about the factors that promote or reduce participation and provide important data for educators, enabling them to proactively monitor factors that put children on the autism spectrum at risk of not achieving their full educational potential.

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Appendix A

List of LASA publications using LASA data up until 30th June 2022 (* indicates publication co-authored with HDR student)

*Adams, D., Keen, D., Heussler, H., Wicks, R., & Roberts, J. (2019). Family outcomes for families of 4-5-year-old children on the autism spectrum who have received early childhood intervention in Australia. *Infants & Young Children, 32,* 186-200. https://doi.org/10.1097/IYC.0000000000000143

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Appendix B

Higher Degree Research (HDR) students contributing to the LASA

The following doctoral, research masters, and honours students worked on the LASA over the course of the study:

There were 2 PhD scholarships funded through the LASA. The first was held by Jac den Houting, who has completed their thesis in 2019 and has since moved to Macquarie University.

> den Houting, J. (2019; PhD). Too anxious to achieve? A quantitative investigation of anxiety and academic achievement in autistic children. *Autism CRC scholar.*

The second funded Kathryn Ambrose for two years. Kathryn has now gone part-time and will submit her thesis in 2023.

> Ambrose, K. (2019-2023; current PhD). Anxiety, autism and academic participation. *Autism CRC scholar.*

There have been many Masters Research students from Education and from Psychology involved with and working on the LASA:

> Poulson, R. (2015 – 2017; Masters of Education and Professional Studies – Research). Parent perceptions of adaptive behaviour changes in their child with autism following their transition to school.
>
> Taylor, S. (2016 – 2017; Masters of Education and Professional Studies – Research). Parent attitudes regarding the schooling options available for their primary aged children diagnosed with autism.
>
> Ambrose, K. (2017-2019; Masters of Education and Professional Studies – Research). Gender differences in the experiences of children with anxiety and high-functioning autism.
>
> Ryan S. (2017 – 2019; Masters of Education and Professional Studies – Research). A study of restricted and repetitive behaviors (RRBs) in two age groups of children from results from the Longitudinal Study of Australian Students with Autism (LASA).

Stainsby, M. (2018-2019; Masters in Clinical Psychology:). Mothers with and without autism spectrum disorder: Parenting stress and family outcomes. (Passed with no amendments and awarded APS College of Clinical Psychologists Student Prize.)

Davis, L. (2018-2020; Masters of Education and Professional Studies – Research). Language development profiles of minimally verbal children on the autism spectrum. (Passed with no amendments, Received Award of Excellence in a Research Thesis.)

There is also one current Masters Research student working with LASA data:

Harrison-Claridge, R. (2021-2023; current Masters of Education and Professional Studies – Research). Parent reported signs of anxiety in minimally verbal children on the autism spectrum.

There were also three Psychology honours students involved in the LASA who have completed their degrees:

Wicks, R. (2017; Psychology Honours). Predictors and correlates of family outcomes of early intervention for young children with autism spectrum disorder. (Awarded APS Medal for highest scoring thesis in cohort.)

Survana, V. (2019; Psychology Honours). A longitudinal study of the relationship between maternal stress and disruptive behaviours in preadolescent children on the autism spectrum.

Cramley, L. (2017, Psychology honours). The use of pharmacology and complementary and alternative medicines among children with autism.

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Our values

Inclusion

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

Innovation

New solutions for long term challenges

Evidence

Guided by evidence-based research and peer review

Independence

Maintaining autonomy and integrity

Cooperation

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

Australian Government
Department of Industry, Science, Energy and Resources

AusIndustry
Cooperative Research Centres Program