WHO ATTENDS AEIOU?

A profile of 922 autistic preschoolers engaged in full-time early intervention in Australia

Jessica Mead | Tae-Jun Lee | Ashleigh Bullot

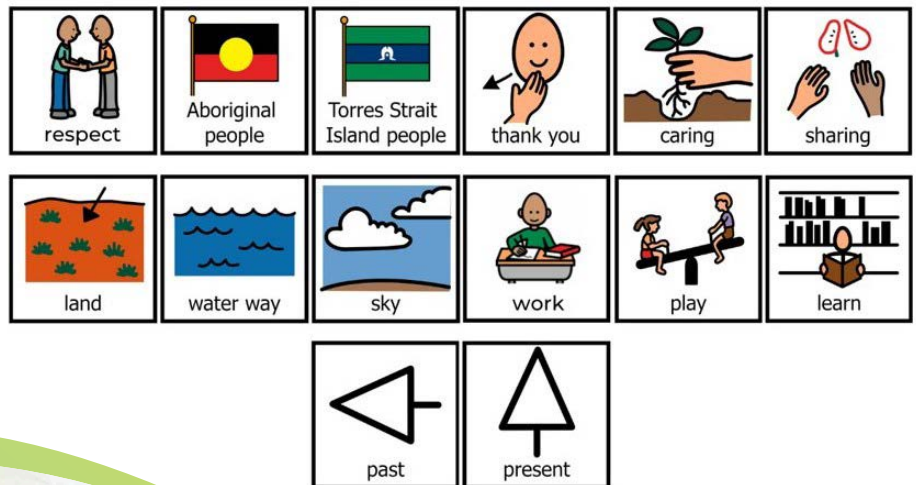AEIOU Foundation, Brisbane, Queensland, Australia

ACKNOWLEDGMENT OF COUNTRY

AEIOU Foundation acknowledges and pays respect to the past, present, and future Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual, and educational practices of Aboriginal and Torres Strait Islander peoples.

In the spirit of reconciliation, we are committed to educating the children in our care about the living culture, history, and achievements of First Nations peoples by embedding a genuine culture and learning framework in our centres.

Our centres operate on unceded land belonging to the Kaurna people (Adelaide), the Ngunnawal, Ngunawal, and Ngambri peoples (Canberra), Bundjalung country (Gold Coast), the Turrbal and Yuggera people (Nathan, Logan, Camira, Bald Hills), the Jagera and Giabal people of Barunggam country (Toowoomba), the Gubbi Gubbi people (Sippy Downs), the Taribelang, Kabi-Kabi, Batjala and Waka-Waka people of Gureng Gureng country (Bundaberg), the people of Gugu-Badhun country (Townsville).

This is a representation of the Acknowledgement of Country using images from the Picture Exchange Card System (PECS), a tool used in our centres to develop functional communication skills with our children.

respect	Aboriginal people	Torres Strait Island people	thank you	caring	sharing
land	water way	sky	work	play	learn
past	present				

SUMMARY

Background

Autism spectrum disorder (ASD), or autism, is a very diverse condition, and people diagnosed with ASD can require varying levels of support. Currently, little research has been done on the characteristics of autistic children with high support needs. To help understand more about this group, AEIOU profiled 922 children who attended our service between 2014 and 2023. AEIOU is a full-time early intervention service for children with ASD, and operates out of 11 centres across Australia. Thanks to the families who volunteered their data for research, AEIOU holds one of the largest datasets on autistic children under six. Through this data, we hope to improve our understanding of autistic children with high support needs and the unique challenges they face.

Findings

> 3.8 males attended AEIOU for every female. This cohort also had a **high percentage of culturally and linguistically diverse (36%) and Aboriginal or Torres Strait Islander (7.4%) families**. However, we found a lower-than-expected percentage of families speaking a language other than English at home (17%).

> We found **a 17-month delay** from the age of first concern to the age of diagnosis, and a **further 10-month delay** from the age of diagnosis to age of enrolment at AEIOU. Overall, there was an average of a 27-month (or 2.3 year) delay from the age of first concern to the age of enrolment at AEIOU.

> Clinical measures showed **considerable early learning and adaptive challenges**, beyond what is typically seen in autistic children. The greatest early learning challenges were in receptive and expressive language, and the greatest adaptive challenges were in communication and socialisation.

> Parent stress and family experiences were consistent with what is typically seen in families of autistic children, with **15% of parents meeting the threshold for high stress, and 30% of parents meeting the threshold for clinically high stress**. This highlights the importance of proactively addressing parental stress in interventions and support programs for families of autistic children.
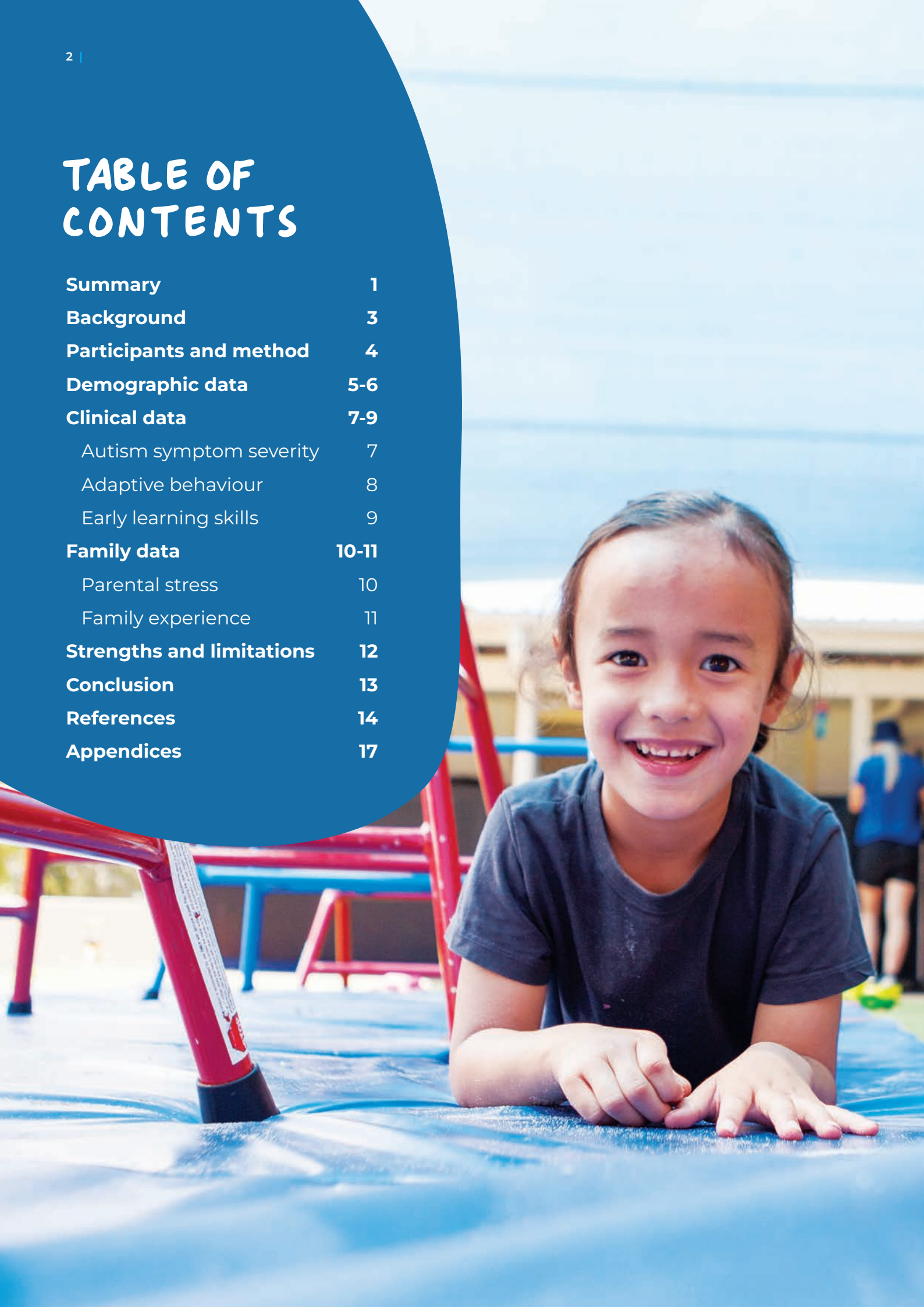
Key recommendations

> Policy work is required to increase availability of diagnostic services and ensure ample opportunities for access to early intervention.

> Diagnostic and early intervention supports need to be tailored so families who with lower English proficiency have fair and equitable access.

> Early intervention programs targeted at similar cohorts of children should pay particular attention to improving outcomes of greatest clinical need.

> Early intervention and support programs for families of autistic children should consider and proactively design their programs to address parental stress.

TABLE OF CONTENTS

BACKGROUND

Autism spectrum disorder (ASD), or autism, is a lifelong neurodevelopmental condition. People diagnosed with ASD experience difficulties in social interaction and communication, and often display restricted and repetitive behaviours (1). While ASD was originally classified as a rare and severe condition, the diagnostic criteria have since broadened to capture a larger range of challenges and behaviours (2). Today, autism is considered to be a very diverse condition requiring different levels of intervention and support.

Autism diagnoses in Australia have increased by 25% from 2015 to 2018, with autism rates now estimated at 1.3% of males and 0.4% of females (3). As diagnoses continue to rise, there is a growing need to better understand the characteristics of those being diagnosed with autism. This is particularly important for children, who are the largest-growing subgroup of those diagnosed. For instance, in Australia, over half of those diagnosed with autism are under fourteen years of age (3).

As autism is a widely diverse condition, it is also important to learn more about autistic people with different skills and abilities. Currently, little is known about the characteristics of autistic children with high support needs, despite the fact this cohort will likely require the most intensive and lifelong care. This report contributes to our understanding of this subgroup by building a profile of 922 children who attended AEIOU between 2014 and 2023. AEIOU is one of the largest full-time autism early intervention services in Australia, and operates out of 11 centres nationwide. Full-time early intervention is often recommended for autistic children with high support needs, with the aim of enhancing their developmental progress and improving long-term outcomes (4,5).

This report presents demographic, clinical and family data collected upon entry to AEIOU, and **represents one of Australia's largest clinical datasets on autistic children under six**. Through this data we hope to improve our understanding of autistic children with high support needs and the specific challenges they face.

PARTICIPANTS AND METHOD

All children in this report attended one of 11 AEIOU early intervention centres across Australia (nine in Queensland, one in South Australia, one in ACT; see Appendix A for more detailed information). Children attended between February 2014 and December 2023. Upon each child's enrolment to AEIOU, parents are asked about their interest in volunteering their data for research purposes. Around half (51%) of 1,812 families volunteered to contribute their data for research.

To be eligible for entry to AEIOU, children needed to be aged between 24 and 77 months and have either a confirmed diagnosis of ASD or be currently undergoing an investigation for ASD. Most children had obtained a diagnosis of ASD before enrolment. However, some had a diagnosis of global developmental delay (1) and were investigating an autism diagnosis upon entry.

Clinical measures were completed upon entry by clinical assessment specialists, staff holding psychology (honours) degrees and specialised training in administering clinical assessments. Parents and caregivers were also invited to complete a demographic questionnaire and a series of family measures. All measures were considered optional.

DEMOGRAPHIC DATA
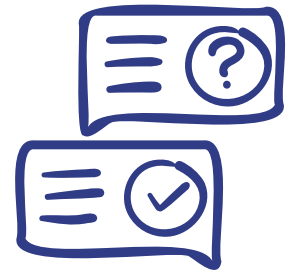
A questionnaire was provided to all families enrolling at AEIOU to learn about their child and families' background. Of the children enrolled, 21% were female and 79% were male. The average age at entry to AEIOU was 46.3 months, or 3.9 years of age. Over a third of children were from a culturally and linguistically diverse background (36%), while 7.4% were from an Aboriginal or Torres Strait Islander background. 17% spoke a language other than English at home.

**Table 1.** **Demographic characteristics of cohort at entry to AEIOU**

Characteristics	*M*	*n*	%
Sex			
Female		192	21%
Male		730	79%
Age			
Age of first concern (months)	18.7	782	
Age at diagnosis (months)	35.9	647	
Age at entry (months)	46.3	880	
Culturally and linguistically diverse			
Yes		277	36%
No		499	64%
First Nations Status			
Aboriginal		53	7%
Torres Strait Islander		3	0.4%
Not Indigenous		656	90%
Prefer not to answer		16	2%
Primary language spoken at home			
English		607	83%
Other		124	17%

M = mean (average), **n** = number of people, **%** = percentage

For every 3.8 males there was one female attending AEIOU (3.8:1 ratio), which is higher than the 3:1 ratio suggested in a recent large study (6). However, that study did find that male-to-female ratios are often higher in groups that only recruit autistic people and do not screen the general population. As most of the children attending AEIOU had already obtained an autism diagnosis, the true ratio may be lower than what was found in this report. Still, our results support the idea that there are generally far more autistic males than females being identified and seeking early intervention.

We found a 17-month delay from the age of first concern to diagnosis and a further 10-month delay from diagnosis to enrolment at AEIOU. **That's an average delay of 2 years and 3 months from when parent first becomes concerned about their child to them actually being able to access the support their child needs.** These delays are not surprising considering the challenges involved in accessing diagnosis and early intervention services in Australia (7–9). Recent studies in Australia have suggested wait times of between 1 to 3.3 years to access diagnosis and assessment services (10,11). Work needs to be done to streamline these processes and ensure opportunities to access early intervention are not missed. AEIOU can leverage the collective voice of our families and staff, using this data, to advocate this need to state and federal governments.

Figure 1. Demographic characteristics of cohort at entry to AEIOU

Sex

Culturally & Linguistically Diverse

First Nations

Language Spoken at Home
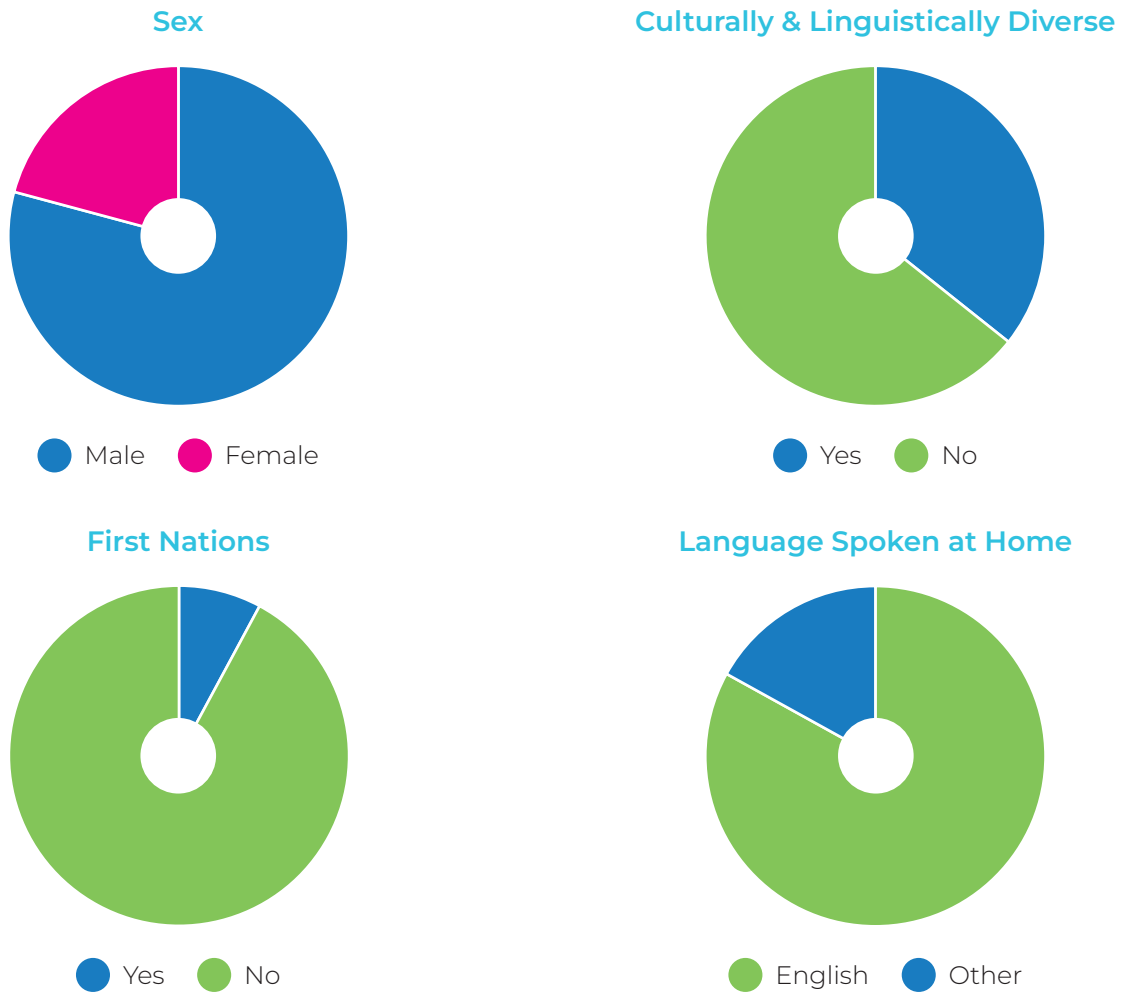
The percentage of culturally and linguistically diverse and First Nations individuals in our cohort is higher than the general Australian population estimates of 28% and 3.8%, respectively (12,13). Interestingly, the percentage of those who spoke a language other than English at home was lower than the Australian population estimates of 23% (12). This suggests that while there may have been reductions in cultural barriers to accessing diagnostic and support services, they may still be present for those with poorer English language skills.

Caregiver education and employment data can be seen in Appendix B. We found most caregivers in this sample had completed an undergraduate or postgraduate degree (62% of primary caregivers, 56% of secondary caregivers), which is a much higher percentage than the Australian population (32%) (14). This result suggests particular socioeconomic advantages within this cohort, as higher levels of education are often associated with higher incomes. This finding is not surprising given access to autism diagnoses are not covered by the National Disability Insurance Scheme (NDIS) and can often exceed $1,500. Additionally, while the NDIS can cover direct intervention costs, other expenses like transportation and taking time off work remain difficult for low-income families to accommodate. Therefore, it is unlikely this sample represents the population of children *requiring* early intervention, but rather those who both require early intervention and have the means to access it.

Employment data is more difficult to interpret as we do not know the separation status of parents and caregivers. However, our results suggest an overall trend towards traditional family structures, with secondary caregivers more likely to work full-time (69%), and primary caregivers more likely to either work part-time (32%) or have full-time home or carer duties (29%).

CLINICAL DATA
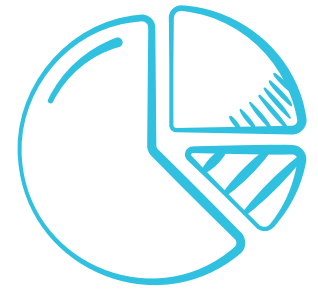
Autism symptom severity

The Autism Diagnostic Observation Schedule (2nd Edition) (15) was used to confirm each child's autism diagnosis and assess symptom severity. A Calibrated Severity Score is used to determine symptom severity, ranging from a low of 1 and a high of 10. This scoring also works to categorise children as either "autistic", "autism spectrum" or "non-spectrum" (15).

Table 2. **Autism classification and symptom severity of cohort at entry to AEIOU**

Autism Diagnostic Observation Schedule (2nd edition)	M	n	%
Calibrated Severity Score (Total Score)	6.5	636	
Classification			
Autism		497	78%
Autism spectrum		120	19%
Non-spectrum		19	3%

M = mean (average), **n** = number of people, **%** = percentage

Figure 2. **Autism classification of cohort at entry to AEIOU**

- Autism
- Autism spectrum
- Non-spectrum
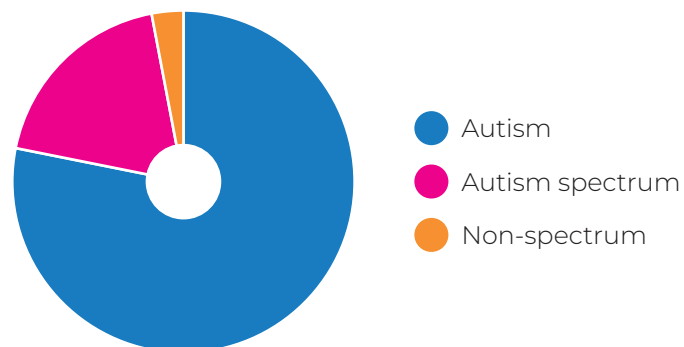
All participants within this sample had obtained (or were seeking) an autism diagnosis prior to enrolling at AEIOU. Scores on the Autism Diagnostic Observation Schedule generally supported this, with only 3% of children failing to meet cutoffs, and 97% of children being classified as autism or autism spectrum. The high number of children in the 'autism' (78%) rather than the 'autism spectrum' (19%) category suggests that the majority of participants in the sample are likely to have more pronounced symptom severity.
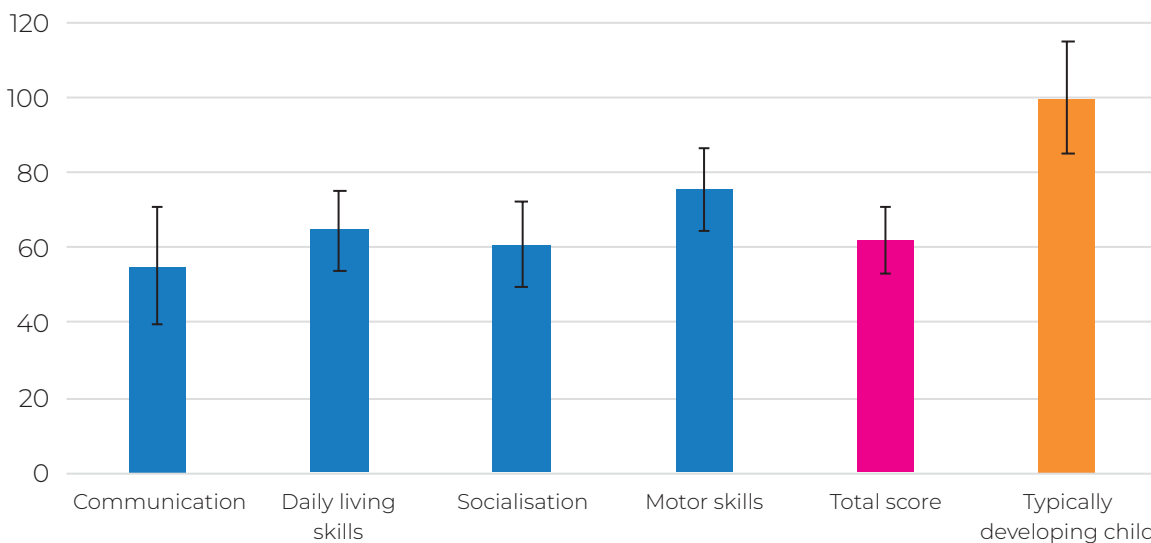
Adaptive behaviour

Adaptive behaviour is different from intelligence. It is a set of conceptual, social and practical skills that allow people to best function in their daily lives. Autism is commonly associated with difficulties in adaptive behaviour (16,17). The Vineland Adaptive Behaviour Scale (2nd and 3rd Edition) was used to assess adaptive functioning across four areas: communication, daily living skills, socialisation, and motor skills (18,19). Scores across all areas were combined into a total score. For all scores, the mean score for typically developing children is 100.

Table 3. Adaptive behaviour of cohort at entry to AEIOU

Vineland Adaptive Behaviour Scale (2nd and 3rd Edition)	*M*	*n*
Communication	55.2	849
Daily living skills	64.7	849
Socialisation	61.0	849
Motor skills	75.5	847
Total score	62.1	849

M = mean (average), ***n*** = number of people

Figure 3. Adaptive behaviour of cohort at entry to AEIOU

Error bars represent one standard deviation above and below the mean. 68% of scores will be between these bars.

Scores on the Vineland Adaptive Behaviour Scale were substantially lower than the average for typically developing children. Scores were lowest in the communication subscale, followed by socialisation and daily living skills. Motor skills demonstrated the highest score across all domains.

While these scores were lower than the expected range for typically developing children, they were also lower than the expected range for autistic children. In a study of 9,067 autistic individuals, the mean total score was 71.58, 9.5 points higher than our sample (16). These lower-than-expected scores were also observed across all four domains. Adaptive behaviour predicts multiple key outcomes for autistic people, including educational attainment and the likelihood of living independently (16). Because of this, our families require support in building adaptive skills when children are at this early age – something AEIOU actively aims to facilitate.

Early learning skills

Autism is often associated with early learning difficulties, though the level of difficulty can vary (1). The Mullen Scales of Early Learning (20) is an assessment of early developmental skills, and is often used to assess cognitive functioning in young autistic children (21–23). We measured early learning skills across four domains: visual reception, fine motor, receptive language, and expressive language. Domains are calculated as percentile scores, with a low of 1 and a high of 99. Percentile scores show the percentage of scores that a particular score surpassed. For example, a percentile score of 75 means that this score was higher than 75% of scores of children the same age. Developmental Quotient (DQ) scores were also calculated by combining data from all four subscales. The mean DQ for typically developing children is 100.

Table 4. **Early learning skills of cohort at entry to AEIOU**

Mullen Scales of Early Learning	*M*	*n*
Visual reception	6.4	858
Fine motor	4.3	786
Receptive language	3.4	856
Expressive language	3.4	719
Developmental Quotient (DQ)	49.4	857

M = mean (average), *n* = number of people, **%** = percentage

Figure 4. **DQ scores of cohort at entry to AEIOU**
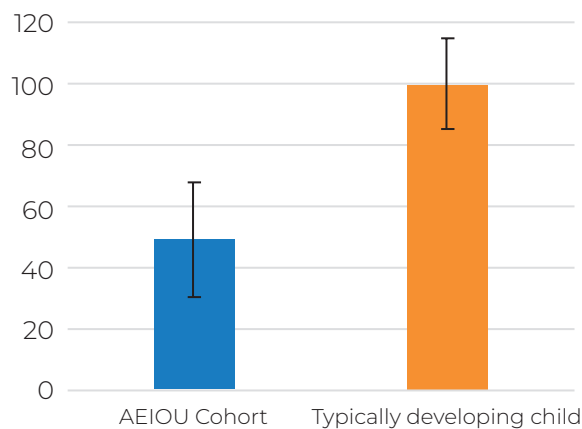
Error bars represent one standard deviation above and below the mean. 68% of scores will be between these bars.

Overall, this sample displayed large delays in cognitive functioning upon intake, with a mean DQ score considerably below the average for typically developing children. When looking at individual domains, there appear to be substantial challenges in all early learning areas, with percentile scores ranging from 3.4 to 6.4. The poorest percentile performance was in expressive language and receptive language, followed by fine motor and visual reception.

As well as being lower than typically developing children, DQ scores of this sample were also lower than those in many other ASD studies. While one Australian study of autistic preschoolers recorded similar DQ scores to this sample (53.46) (24), several other studies with similar samples reported much higher DQ scores, ranging from 59.4 to 73.3 (25–29). This finding is important as cognitive functioning in autistic children can predict long-term progress in many outcome areas, including symptom severity, adaptive skills, social-communication skills and linguistic skills (29–33).

FAMILY DATA

Parental stress

Parents and caregivers of autistic children often have higher levels of stress than parents of typically developing children (34–37). This is important as stress can disrupt a caregiver's mental health and damage the relationship between themselves and their child (34,38). For this report, parenting stress was measured using the Parenting Stress Index (4th Edition, Short-Form), a 36-item survey form given to the primary parent or caregiver (39). This measure provides scores on three subscales: parental distress, parent-child dysfunction and difficult child, each with a possible range of 12 to 60. Scores are then combined to give an overall measure of parental stress ranging from 36 to 180.

Table 5. Parental stress of cohort at entry to AEIOU

Parenting Stress Index (4th Edition, Short-Form)	*M*	*n*
Parental distress	34.4	113
Parent-child dysfunction	30.4	113
Difficult child	36.4	113
Total score	101.9	806

M = mean (average), ***SD*** = standard deviation, ***n*** = number of people

Figure 5. Parental stress of cohort at entry to AEIOU

- Typical Stress
- High Stress
- Clinically High Stress
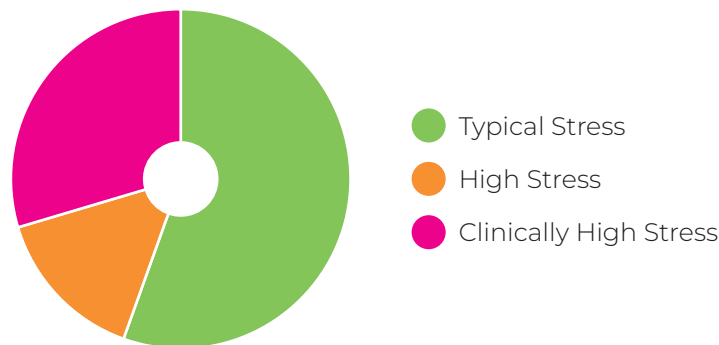
Average scores amongst our cohort were in the 78th percentile, meaning parents and caregivers in our cohort were more stressed than 78% of other caregivers. Most concerningly, 15% of parents met the threshold for high stress, and 30% of parents met the threshold for clinically high stress (see Figure 5). Scores amongst the three subscales were also relatively equal, which suggests our caregivers face multiple stressors related to different aspects of parenting.

We found scores on this measure were similar to those reported in previous studies of parents of autistic children (36). These findings support existing evidence that raising a child with ASD can be very stressful for parents. Therefore, it is important to proactively address parental stress in interventions and support programs for families of autistic children. This is something AEIOU actively strives to achieve though our parent engagement and capacity-building sessions, and by providing confidential counselling for parents and caregivers through its Employee Assistance Program (EAP).

Family experience

Parents of autistic children face unique challenges that impact their family wellbeing and quality of life (40). To assess the family experience in this sample, we used the Autism Family Experience Questionnaire. This is a specialised measure designed to assess the family experience and quality of life in families of autistic children (40). This measure is a 48-item questionnaire filled out by parents or caregivers of the autistic child. This measure contains four subscales: the experience of being a parent of a child with autism, family life, child development and child symptoms. To allow us to compare results across different subscales, we converted all scores to a 0-100 scale, with greater scores indicating better outcomes.

Table 6. Family experience of cohort at entry to AEIOU

Autism Family Experience Questionnaire	*M*	*n*
Experience of being a parent of a child with autism	61.3	120
Family life	54.7	120
Child development	39.2	119
Child symptoms	55.3	119
Total score	52.2	119

M = mean (average), ***n*** = number of people

Figure 6. Family experience of cohort at entry to AEIOU
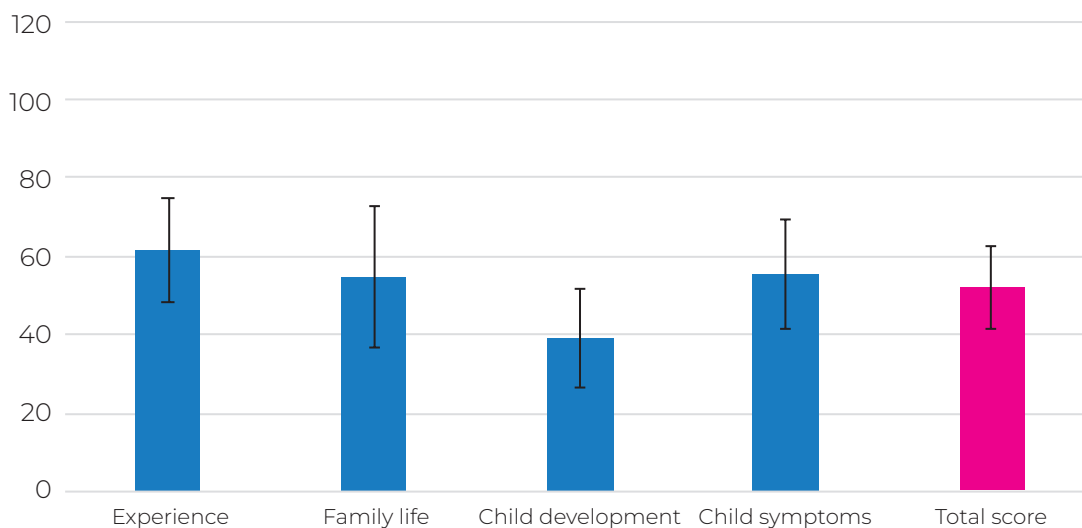
Error bars represent one standard deviation above and below the mean. 68% of scores will be between these bars.

Overall, we found the child development subscale to have the poorest performance, followed by family life, child symptoms, and the experience of being a parent of a child with autism. These scores are similar to those found in the original study that developed this measure (40), meaning our findings are similar to those seen in other parents of autistic children.

STRENGTHS AND LIMITATIONS

Strengths

This report has several strengths:

1. We profiled a very large cohort of 922 children over a 10-year period. Our findings represent a large portion of Australian children and families, and are well-positioned to advocate for the needs of autistic children and their families at a local, state and federal level.

2. The measurements we applied are well-used and widely accepted. This means we have been able to compare our findings to other studies with the same measurement tools, and to consider how our cohort compares to other samples of autistic children.

3. It addresses a key gap in the literature by looking specifically at the characteristics of autistic children with high support needs. This targeted approach contributes valuable insights into a group who will face distinct challenges and needs, and who are likely to require intensive and lifelong support.

Limitations

Despite its strengths, this report has the following limitations:

1. Only 51% of families consented to provide their data for research purposes. This may have introduced self-selection bias, where families that volunteer their data are different in important ways from those who do not.

2. While this cohort contains children who are enrolled in full-time early intervention, the findings are not likely to represent all children who *need* this level of support. Because getting an autism diagnosis and accessing early intervention in Australia can be challenging, this sample likely consists mainly of families who can afford to access and manage these services. Future research should focus on including those who might not be well-represented in this report, like families with lower socioeconomic status and those who speak languages other than English, for a better understanding of their unique strengths and challenges.

3. Not all measures in this report have the same number of respondents. This is mainly because our measures are considered optional, and families can choose not to complete any measure or question. Additionally, some measures were introduced after data collection started (such as the Autism Family Experience Questionnaire, which was introduced in 2022) or were not digitised until later (such as the Parenting Stress Index, where subscale scores were only digitised after 2023). This missing data limits our ability to draw strong conclusions across all measures. However, because such a large sample size was used, even the measure with the lowest participants (n = 113) is substantially higher than many other studies on autistic children.
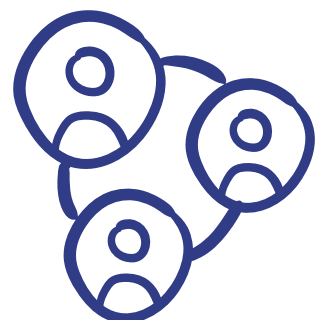
CONCLUSION

This report created a profile of the demographic, clinical and family characteristics of 922 autistic children who attended AEIOU over 10 years. Given the large scope of this report, we are now better equipped to understand autistic children with high support needs in Australia. Understanding this cohort is important, as those with the greatest support needs will likely experience unique challenges in school, work and social settings. By better understanding this cohort, professionals such as early intervention providers, healthcare practitioners, policymakers and funders are better able to anticipate their unique needs and ensure efforts are made to meet them as they progress through childhood and beyond.

Key recommendations:

1. The pathway to accessing critical early intervention in autistic Australian children with high support needs is clunky and lengthy. Policy changes are required to increase the availability of diagnostic services and ensure ample opportunities for access to early intervention.

2. There are fewer families speaking a language other than English in our cohort than we would expect, based on Australian data. Diagnostic and early intervention supports need to be tailored to ensure families with a lower English proficiency are have fair and equitable access.

3. Clinical measures show the greatest early learning challenges were in receptive and expressive language, and the greatest adaptive challenges were in communication and socialisation. Early intervention programs targeting similar cohorts of children should pay particular attention to improving outcomes of greatest clinical need.

4. Our findings indicated a high proportion of parents met thresholds for high and clinically high stress. Early intervention and support programs for families of autistic children should consider this and proactively design their programs to address parental stress.

REFERENCES

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. American Psychiatric Association; 2013.

2. American Psychiatric Association. Autism Spectrum Disorder [Internet]. Washington, D.C.; 2013. Available from: https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM-5-Autism-Spectrum-Disorder.pdf

3. Australian Bureau of Statistics. Australian Bureau of Statistics. 2019. Disability, ageing and carers, Australia: Summary of findings. Available from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

4. Corsello CM. Early intervention in autism. Infants Young Child. 2005;18(2):74–85.

5. Pasco G. The value of early intervention for children with autism. Paediatr Child Health. 2018 Aug;28(8):364–7.

6. Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. J Am Acad Child Adolesc Psychiatry. 2017 Jun;56(6):466–74.

7. Gibbs V, Aldridge F, Sburlati E, Chandler F, Smith K, Cheng L. Missed opportunities: An investigation of pathways to autism diagnosis in Australia. Res Autism Spectr Disord. 2019 Jan;57:55–62.

8. Taylor LJ, Eapen V, Maybery MT, Midford S, Paynter J, Quarmby L, et al. Diagnostic evaluation for autism spectrum disorder: A survey of health professionals in Australia. BMJ Open. 2016 Sep 6;6(9):e012517.

9. Ward SL, Sullivan KA, Gilmore L. Practitioner perceptions of the assessment and diagnosis of autism in Australia. Aust Psychol. 2016 Aug 1;51(4):272–9.

10. Bent CA, Barbaro J, Dissanayake C. Parents' experiences of the service pathway to an autism diagnosis for their child: What predicts an early diagnosis in Australia? Res Dev Disabil. 2020 Aug;103:103689.

11. Boulton KA, Hodge MA, Jewell A, Ong N, Silove N, Guastella AJ. Diagnostic delay in children with neurodevelopmental conditions attending a publicly funded developmental assessment service: findings from the Sydney Child Neurodevelopment Research Registry. BMJ Open. 2023 Feb 1;13(2):e069500.

12. Australian Institute of Health and Welfare. Australian Government. 2023. Culturally and linguistically diverse Australians. Available from: https://www.aihw.gov.au/reports-data/population-groups/cald-australians/overview

13. Australian Institute of Health and Welfare. Australian Government. 2023. Profile of First Nations people. Available from: https://www.aihw.gov.au/reports/australias-welfare/profile-of-indigenous-australians

14. Australian Bureau of Statistics. Australian Bureau of Statistics. 2023. Education and Work, Australia. Available from: https://www.abs.gov.au/statistics/people/education/education-and-work-australia/may-2023

15. Lord C, Rutter M, DiLavore P, Risi S, Gotham K, Bishop S. Autism diagnostic observation schedule–2nd edition (ADOS-2). California: Western Psychological Corporation; 2012.

16. Chatham CH, Taylor KI, Charman T, Liogier D'ardhuy X, Eule E, Fedele A, et al. Adaptive behavior in autism: Minimal clinically important differences on the Vineland-II. Autism Research. 2018 Feb 21;11(2):270–83.

17. Kanne SM, Gerber AJ, Quirmbach LM, Sparrow SS, Cicchetti D V., Saulnier CA. The role of adaptive behavior in autism spectrum disorders: Implications for functional outcome. J Autism Dev Disord. 2011 Aug 2;41(8):1007–18.

18. Sparrow S., Cicchetti D., Saulnier C. A. Vineland Adaptive Behavior Scales, Third edn. LDN: Pearson; 2016.

19. Sparrow S, Dominic V, Cicchetti DA, Balla DA. Vineland Adaptive Behavior Scales (2nd ed.). MN: AGS: Circle Pines; 2005.

20. Mullen EM. Mullen scales of early learning. MN: AGS: Circle Pines; 1995.

21. Denisova K, Lin Z. The importance of low IQ to early diagnosis of autism. Autism Research. 2023 Jan 13;16(1):122–42.

22. Eapen V, Črnčec R, Walter A. Clinical outcomes of an early intervention program for preschool children with Autism Spectrum Disorder in a community group setting. BMC Pediatr. 2013 Dec 7;13(1):3.

23. Vivanti G, Dissanayake C, Zierhut C, Rogers SJ. Brief report: Predictors of outcomes in the Early Start Denver Model delivered in a group setting. J Autism Dev Disord. 2013 Jul 3;43(7):1717–24.

24. Vivanti G, Paynter J, Duncan E, Fothergill H, Dissanayake C, Rogers SJ. Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting. J Autism Dev Disord. 2014 Dec 29;44(12):3140–53.

25. Ben-Sasson A, Soto TW, Martínez-Pedraza F, Carter AS. Early sensory over-responsivity in toddlers with autism spectrum disorders as a predictor of family impairment and parenting stress. Journal of Child Psychology and Psychiatry. 2013 Aug 21;54(8):846–53.

26. Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, et al. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. Pediatrics. 2010 Jan 1;125(1):e17–23.

27. Godel M, Robain F, Kojovic N, Franchini M, Wood de Wilde H, Schaer M. Distinct patterns of cognitive outcome in young children with autism spectrum disorder receiving the Early Start Denver Model. Front Psychiatry. 2022 Jun 22;13.

28. Rogers SJ, Estes A, Lord C, Vismara L, Winter J, Fitzpatrick A, et al. Effects of a brief Early Start Denver Model (ESDM)–based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. J Am Acad Child Adolesc Psychiatry. 2012 Oct;51(10):1052–65.

29. Zachor DA, Ben Itzchak E. Treatment approach, autism severity and intervention outcomes in young children. Res Autism Spectr Disord. 2010 Jul;4(3):425–32.

30. Fernell E, Hedvall Å, Westerlund J, Höglund Carlsson L, Eriksson M, Barnevik Olsson M, et al. Early intervention in 208 Swedish preschoolers with autism spectrum disorder. A prospective naturalistic study. Res Dev Disabil. 2011 Nov;32(6):2092–101.

31. Gabriels RL, Hill DE, Pierce RA, Rogers SJ, Wehner B. Predictors of treatment outcome in young children with autism: A retrospective study. Autism. 2001 Dec 29;5(4):407–29.

32. Thurm A, Lord C, Lee LC, Newschaffer C. Predictors of language acquisition in preschool children with autism spectrum disorders. J Autism Dev Disord. 2007 Sep 20;37(9):1721–34.

33. Turner LM, Stone WL. Variability in outcome for children with an ASD diagnosis at age 2. Journal of Child Psychology and Psychiatry. 2007 Aug 3;48(8):793–802.

34. Bonis S. Stress and parents of children with autism: A review of literature. Issues Ment Health Nurs. 2016 Mar 3;37(3):153–63.

35. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. J Autism Dev Disord. 2008 Aug 1;38(7):1278–91.

36. Hayes SA, Watson SL. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. J Autism Dev Disord. 2013 Mar 13;43(3):629–42.

37. Pastor-Cerezuela G, Fernández-Andrés MI, Tárraga-Mínguez R, Navarro-Peña JM. Parental stress and ASD: Relationship with autism symptom severity, IQ, and resilience. Focus Autism Other Dev Disabl. 2016 Dec 26;31(4):300–11.

38. Shepherd D, Landon J, Taylor S, Goedeke S. Coping and care-related stress in parents of a child with autism spectrum disorder. Anxiety Stress Coping. 2018 May 4;31(3):277–90.

39. Abidin RR. Parenting Stress Index-short form: Test manual. Charlottesville, VA: Pediatric Psychology Press; 1990.

40. Leadbitter K, Aldred C, McConachie H, Le Couteur A, Kapadia D, Charman T, et al. The Autism Family Experience Questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. J Autism Dev Disord. 2018 Apr 18;48(4):1052–62.

41. Australian Bureau of Statistics. Australian Government. 2023. Socio-Economic Indexes for Areas. Available from: https://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa

APPENDICES

Appendix A. Locations and sample distribution across 11 AEIOU centres

Location	n	%	LGA	SEIFA percentile
Queensland				
Bald Hills	110	12%	Brisbane	90
Bundaberg	59	6%	Bundaberg	16
Camira	143	16%	Brisbane	90
Gold Coast	106	12%	Gold Coast	81
Logan	99	11%	Logan	33
Nathan	131	14%	Brisbane	90
Sippy Downs	56	6%	Sunshine Coast	78
Toowoomba	45	5%	Toowoomba	54
Townsville	70	8%	Townsville	62
South Australia				
Brighton	61	7%	Holdfast Bay	87
ACT				
Canberra	42	5%	Unincorporated ACT	94

Socio-Economic Indexes for Areas (SEIFA) is a metric developed by the Australian Bureau of Statistics. Greater scores indicate greater socioeconomic advantage in areas such as income, education, employment, occupation, and housing (41). Scores are based on the five-yearly census.

Appendix B. Caregiver education and employment

Characteristics	n	%	n	%
Highest educational level	**Primary caregiver**		**Secondary caregiver**	
No formal education	0	0%	2	0.4%
Primary school up to Grade 9	12	2%	14	3%
Junior Certificate (Grade 10)	48	8%	47	8%
Senior Certificate (Grade 12)	123	19%	129	23%
Tertiary studies (TAFE)	25	4%	16	3%
Tertiary studies (undergraduate degree)	226	36%	155	27%
Postgraduate studies	170	27%	162	29%
Other	19	3%	25	4%
Do not wish to answer	12	2%	16	3%
Employment				
Full-time	145	23%	387	69%
Part-time or casual	203	32%	68	12%
Home carer or home duties	180	29%	28	5%
Self-employed	39	6%	50	9%
Studying full-time	18	3%	3	1%
Studying part-time	14	2%	3	1%
Unemployed	22	4%	16	3%
Other	9	1%	10	2%

n = number of people, **%** = percentage