

# Study of Australian School Leavers with Autism (SASLA)

Parent/Carer Baseline Profile 2019

A longitudinal study of post-school outcomes for young people with and without autism and their parents, 2014 – 2021.

**June 2019** 







## What is the Study of Australian School Leavers with Autism?

The Study of Australian School Leavers with Autism (SASLA) is an online survey-based project, which follows autistic and non-autistic young people aged 15 to 25 years over a 2-year period.

The transition between adolescence and adulthood is an important and difficult milestone for all young people, but one that may be particularly challenging for autistic individuals.

We have also asked parents and carers of autistic individuals about their experience during this time, as we would like to understand this period from their point of view in addition to that of young people.

This report will focus on the data we have received from parents and carers of autistic young people.

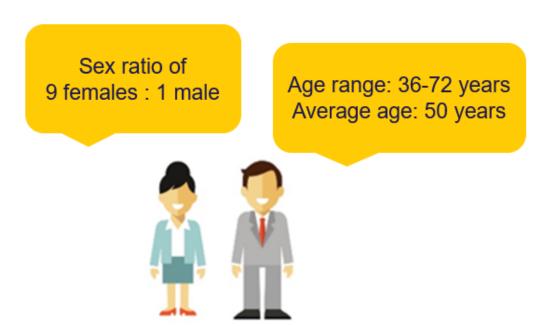
This snapshot provides information on the profile of the parents/carers of autistic young people aged 15-25 years who have completed the first of three surveys.

My son was diagnosed at age 6 and is almost 18. His early intervention is why he does so well now.

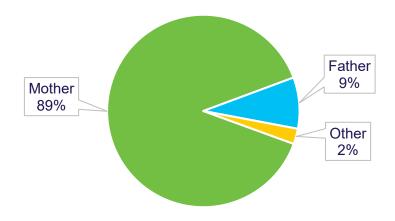


### Who is participating?

We had 117 parents/carers complete the survey. The age of parents/carers ranged from 36-72 years old, with an average age of 50 years.

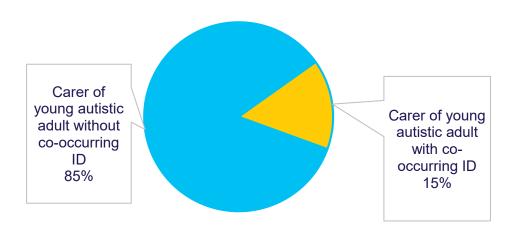


More females than males completed the survey, with a ratio of approximately 9:1. This is consistent with most research targeting parents/carers.





The majority of respondents were mothers or fathers, but we did have some non-parent carers also complete the survey.



The majority of respondents (85%) reported having a child without a co-occurring intellectual disability. This means our data is a little biased toward the experience of parents who have an autistic child without a co-occurring intellectual disability; it may not be representative of parents with an autistic child who has a co-occurring intellectual disability.

#### Location



The majority of the parents/carers lived in Queensland and Victoria, but there were respondents from each state except for the Australian Capital Territory and the Northern Territory.

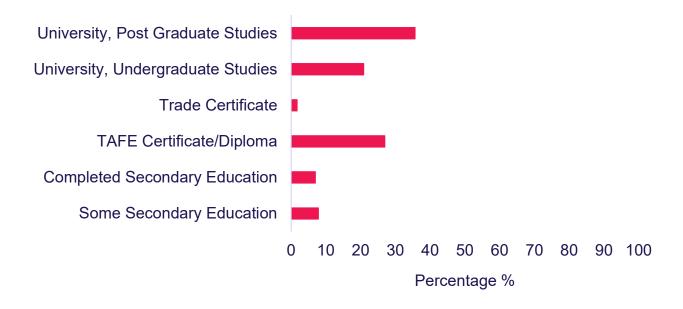


#### Country of Birth



The majority of the parents/carers were born in Australia. Those who were born in other countries were born in Switzerland, Africa, Singapore, Scotland, Russia, Philippines, New Zealand, Malaysia, Ireland, Iran, Hong Kong, England, and Bangladesh.

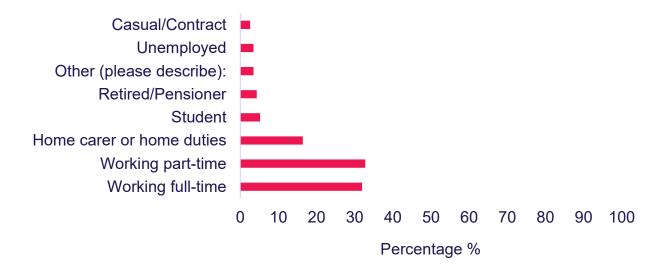
#### Highest level of education



A large proportion of the parents/carers had a TAFE Certificate/Diploma or university degree.

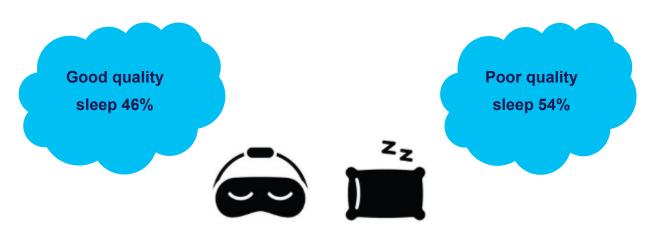


#### Current employment



In terms of employment, most parents/carers were either working full time (32%), part time (33%), or were fulltime carers (16%).

#### Sleep



Respondents answered questions about sleep using a standard sleep measure. Over half of the parents/carers reported experiencing poor sleep quality.

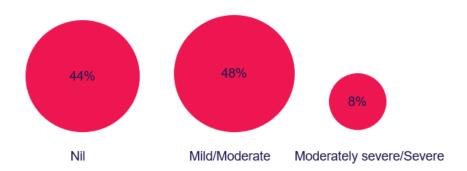
My daughter has a sleep disorder and I have to help her.



#### Mental health

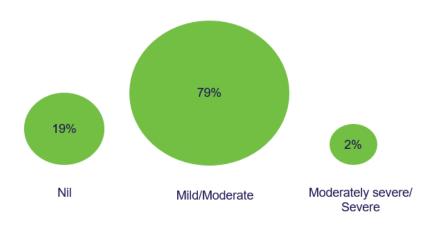
Parents/carers answered questions about their mental health, including depression and anxiety.

#### Depression



56% of parents/carers responded to items in a way that indicated they had been experiencing mild to severe symptoms of depression at the time of the Baseline survey.

#### **Anxiety**



81% of parents/carers responded to items in a way that indicated they had been experiencing mild to severe symptoms of anxiety at the time of the Baseline survey.

Most of my anxiety stems from fear for my autistic daughter's future.



### Social support

Parents/Carers were asked questions about their social support. Here is a summary of their responses to two of these questions.



## "How many people can you really count on to be dependable when you need help?"

1-2 people: 40% 3-4 people: 39%

Over 5 people: 21%

#### "How satisfied are you with this support?"

Dissatisfied 3%

Satisfied 90%

Neutral 7%



#### Where to next?

Some people have already completed follow-up survey at 12 months and even 24 months.

Over the next three years the SASLA team will focus on the 12- and 24-month follow-ups with people who completed the first survey.

We will focus on identifying any challenges experienced by parents and carers of autistic young people, including any changes over time.

The information collected in SASLA will allow us to explore factors that can be targeted for developing appropriate supports for young people and their parents and carers.

My son is very chatty and knowledgeable on his passions but not so good at asking others about theirs!





#### Copyright and disclaimer

The information contained in this report has been published by the Autism CRC to assist public knowledge and discussion to improve the outcomes for people with autism through end-user driven research. To this end, Autism CRC grants permission for the general use of any or all of this information provided due acknowledgement is given to its source. Copyright in this report and all the information it contains vests in Autism CRC. You should seek independent professional, technical or legal (as required) advice before acting on any opinion, advice or information contained in this report. Autism CRC makes no warranties or assurances with respect to this report. Autism CRC and all persons associated with it exclude all liability (including liability for negligence) in relation to any opinion, advice or information contained in this report or for any consequences arising from the use of such opinion, advice or information.

Map by FreeVectorMaps.com <a href="http://freevectormaps.com">http://freevectormaps.com</a>, and sleep icons from Vecteezy.com

ISBN: 978-1-922365-06-4

**Citation:** Flower, R. L., Haschek, A., Lawson, L. P., & Richdale, A. L. (2019). *Study of Australian School Leavers with Autism (SASLA): Parent/Carer Baseline Profile 2019.* Brisbane. Autism CRC.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.





#### Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. The authors would like to acknowledge the research participants who dedicated their time to the project. We further acknowledge Dr Mirko Uljarevic and Dr Ru Ying Cai for project establishment and data collection, and members of the Autism CRC Program 3 team who contributed to project content and recruitment. Staff and non-staff in kind support, including recruitment, was also provided by Autism CRC and Other participants (here), other autism associations, a Victorian Secondary School, and many other individuals. We would like to thank Mick Leahy for his work in designing and formatting the report.

#### The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (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.





