AutismCRC

Longitudinal Study of Australian School Leavers with Autism (SASLA)

FINAL REPORT

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April 2022

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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.

autismcrc.com.au

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, when speaking of adults, 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'.

This project was established at a time when 'with autism' was commonly accepted language.

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1. Executive Summary

Introduction

Historically, the adult years have been largely ignored in autism research, despite these years representing the greatest proportion of individuals' lives. Hence, limited guidance exists for autistic people and their families about trajectories across the lifespan, and autistic adults often experience high levels of unemployment, mental illness and community disengagement, as well as significant dependency on family members.

Research design and methods

The Cooperative Research Centre for Living with Autism (Autism CRC) established the Longitudinal Study of Australian School Leavers with Autism (SASLA)[1] in 2014. The aim of this project was to collate a comprehensive profile of autistic young people in Australia, aged 15-25 years at entry, as they transitioned into adulthood. The SASLA team were also interested in describing the role and experiences of parents/carers of transition-aged autistic young people. To achieve these aims, SASLA developed - an online survey (3 surveys per participant over 2 years) to assess the background, health and lifestyle characteristics of participants in collaboration with, and with insights from autistic people, their families, autism organisations and researchers. The SASLA survey content was informed by the outcomes of consultation with the autism community and designed to over-lap with the Australian Longitudinal Study of Autistic Adults (aged 25 – 80 years) (ALSAA) on many core variables to enable us to bring these data together to gain a broader, whole-of-life understanding in key areas.

Sample characteristics

The young people who completed the survey at baseline were aged from 15-25 years, mostly Australian-born and English-speaking, and from diverse locations across Australia. There was a higher proportion of males to females in the autistic group and females to males in the non-autistic group. The parents/carers who completed the SASLA survey ranged in age from 36-72 years, were highly educated, mostly Australian-born, English-speaking, and mothers.

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[1] Previously known as the Comprehensive and Unique Profile of Australian School Leavers with Autism.

Baseline	**477 total responses** consisting of 142 autistic young adults (27 with an intellectual disability (ID)), 218 non-autistic young adults, and 117 parent/carers.
1-year	**240 total responses** consisting of 91 autistic young adults (15 with an ID), 65 non-autistic young adults and 84 parent/carers.
2-year	**271 total responses** consisting of 110 autistic young adults (21 with an ID), 65 non-autistic young adults and 96 parent/carers.

Findings

The SASLA survey yielded many important insights into the experiences of Australian young adults and their parents/carers. Autistic young people reported more bullying experiences and perceived a lack of support in education and employment settings. Despite this, they were just as likely as non-autistic peers to complete higher education and function independently in post-school settings; however, they had less paid employment.

Mental health diagnoses (anxiety and/or depression) and ADHD were more prevalent among autistic than non-autistic young people. Poor mental health was associated with multiple, interrelated risk factors: female gender, more autistic traits, feelings of loneliness/worry, dissatisfaction with social supports, intolerance of uncertainty, and dispositional emotion characteristics. The presence of mental health difficulties, in turn, predicted an increased risk for sleep difficulties, lower quality of life, and suicidal thoughts and behaviours.

Parents/carers of autistic young adults also reported mental and physical health challenges and a perceived lack of support. The abilities and strategies used by autistic young people and their parents/carers to deal with distress were found to relate to differences in mental health symptoms, suggesting there may be therapeutic benefit in supporting adaptive strategy use.

The information provided by SASLA participants contributed to the critical evaluation and refinement of established measures for use with autistic people:

- Hospital Anxiety and Depression Scale (HADS)
- Patient Health Questionnaire-9 (PHQ-9)
- Impact of Diagnosis Scale
- Brief COPE Inventory
- Vocational Index for Adults with Autism

Lastly, in 2020 we explored the impact of the COVID-19 pandemic on a small sample of Australian young people, finding that those on the autism spectrum were twice as likely to report the pandemic as having a very negative impact on their lives than non-autistic young adults.

Utilisation

Findings from the SASLA survey have been utilised and disseminated widely to the autistic community (individuals, families, organisations, professionals) and the international research community, through 16 peer-reviewed publications with SASLA data (plus 4 currently under review), 55 presentations, 30 media outputs, and 14 resources for end-users.

The SASLA team also contributed to Federal and State policy through six Select and Senate enquiries and consultation on areas of expertise resulting in two invitations to appear before the committees. In addition, SASLA has provided professional development, research support and career opportunities for 6 early career researchers, 6 postgraduate students, 5 Honours students and 2 undergraduate placement students.

Implications for research and practice

Findings from the SASLA survey have a range of implications for research and clinical practice including the need for:

1. Timely and accurate mental health assessments, with the HADS and PHQ-9 as possible screening options. The Brief COPE can also be used to examine coping strategies.
2. Timely and individualised mental health supports promoting adaptive self-regulation behaviour, psychological flexibility, good sleep quality, and social supports.
3. More research focused on characterising and unravelling the interplay of risk and resilience factors for mental health difficulties.
4. More research using instruments that are suitable for autistic people, with findings that can be generalised to real-world contexts, and using a longitudinal research design.
5. Development and evaluation of psychological treatments for common mental health and sleep difficulties co-occurring in autism (co-production is highly recommended).

Recommendations

We make the following recommendations for the improvement of research and practice:

1. A **National Autism Plan** should be developed in consultation with autistic individuals, families, autism organisations, service providers and researchers.
2. The Federal government must commit to **reducing the age of autism diagnosis** so that there are increased opportunities for earlier access to supports for autistic people. Through the provision:
    - Of a national training package for educational, medical, and allied health staff on the early presentation of male and female autistic phenotypes to reduce the age of diagnosis, particularly in girls.
    - Of increased Commonwealth places in relevant clinical degrees to increase the number of qualified diagnosticians leading to improved access to a timely diagnosis.
    - Access to subsidised diagnosis for adolescent and adult referrals.
3. A national **bullying plan** to tackle the pervasive bullying and social exclusion encountered in Australian schools.
4. Develop National guidelines to **increase social inclusion and participation** for autistic people from childhood onwards in education, employment and within the wider community.
    - To be developed with autistic people, autism peak bodies, community groups, service providers and families.
5. Introduce **guidelines for the NDIS** on providing accessible individual/carer supports in the pre-planning stage of applying for NDIS funding for those with autism. To include - detailed explanations and examples of available supports (in their area) and how to best plan an application that addresses both individual and family needs.
6. Governments must urgently provide specialised, accessible and **evidence-based mental health supports** for autistic people and their family/carers.
7. Create **National Training Packages** to increase knowledge and awareness of autism:
    - **For the workplace** - including reasonable workplace adjustments, strategies for supporting individual differences and mental health supports. Disability Employment Service (DES) providers should be included in any training and consultation with autistic adults about their needs and experiences will be paramount.
    - **For mental and physical healthcare service providers** - about the unique clinical presentation of co-occurring conditions in autism and on the appropriate use of validated tools to identify and inform the treatment of these conditions. Developing preventative strategies will also be important. The team notes that in the SASLA

age group, physical health is generally less of a concern but, international research indicates that autistic adults are more at risk of physical health conditions than is the general population. Thus, developing preventative strategies would be useful for autistic people in the SASLA age range.

   - **For education providers** to understand how to provide appropriate supports that can assist autistic students to thrive in educational settings.
   - To provide **easy access** to the **best advice** for autistic clients from *all* service providers. This must be developed in consultation with autistic individuals, families, autism organisations, service providers and researchers.

8. Secure and reliable long-term funding for future **autism research** to further support autistic people to improve knowledge about:
   - Barriers and supports required to improve employment and vocational outcomes.
   - Predictors of physical health, mental health, and well-being leading to improved supports and support availability for autistic people.
   - Protective factors that can be targeted by clinicians to buffer risk factors associated with the poor physical and mental health outcomes, and reduced well-being that are so common in autism.
   - Measures of which are valid and reliable for use in autistic populations.
   - How sleep affects mental health and quality of life.
   - Effective preventative and intervention strategies to address the societal and health challenges faced by autistic adolescents and adults.
9. Transition supports:
   - Equip services and develop supports for successful transition of autistic adolescents from school into further education and employment.
   - Provide support and information for parents/carers of autistic youth transitioning from high school into further study and employment.
   - Existing supports must be made more available and accessible for autistic adolescents leaving school and entering a new study/employment environment. For example, work experience initiatives, life skills and independent living courses, access to school councillors, and equity and diversity staff on university and vocational education campuses.
   - The 10 recommendations of the Victorian DHS Final report “Supporting transition to and participation in tertiary education for students with an Autism Spectrum Disorder” (Richdale et al., 2012) are still relevant and are supported by SASLA research therefore they should be actioned by government.

2. Background

The Autism CRC Programs of research take a whole-of-life view from diagnosis and the early years, through the school years and into adult life. The SASLA study sits within Program 3 – Adulthood[2] which aims to improve opportunities for autistic people to successfully participate in higher education and employment and identifying best practice in physical and mental health management. The transition between adolescence and adulthood is an important and difficult milestone for all young people. SASLA surveyed autistic (with and without an intellectual disability) and non-autistic youth, and the parents/carers of autistic youth so that we could build an accurate picture of the experiences of autistic people aged 15 to 25 years of age in Australia. The surveys were developed in 2014-15 with extensive community consultation and the baseline survey commenced in May 2015. SASLA was initially funded to June 30, 2017 and it was subsequently extended to June 30, 2021. For a full timeline of the project see Figure 1.

The **aims** of this project are to:

- Identify and describe concurrent educational and vocational outcomes, as well as change over time.
- Identify concurrent physical, mental health and well-being outcomes, as well as change over time.
- Identify predictors, both concurrent and longitudinal, of educational, vocational, health and well-being outcomes for young people.
- Describe the health and well-being of parents/carers of young autistic Australians and identify risk and resilience factors contributing to parents/carer outcomes.
- Use the survey data collected to validate existing scales for use in young autistic Australians.

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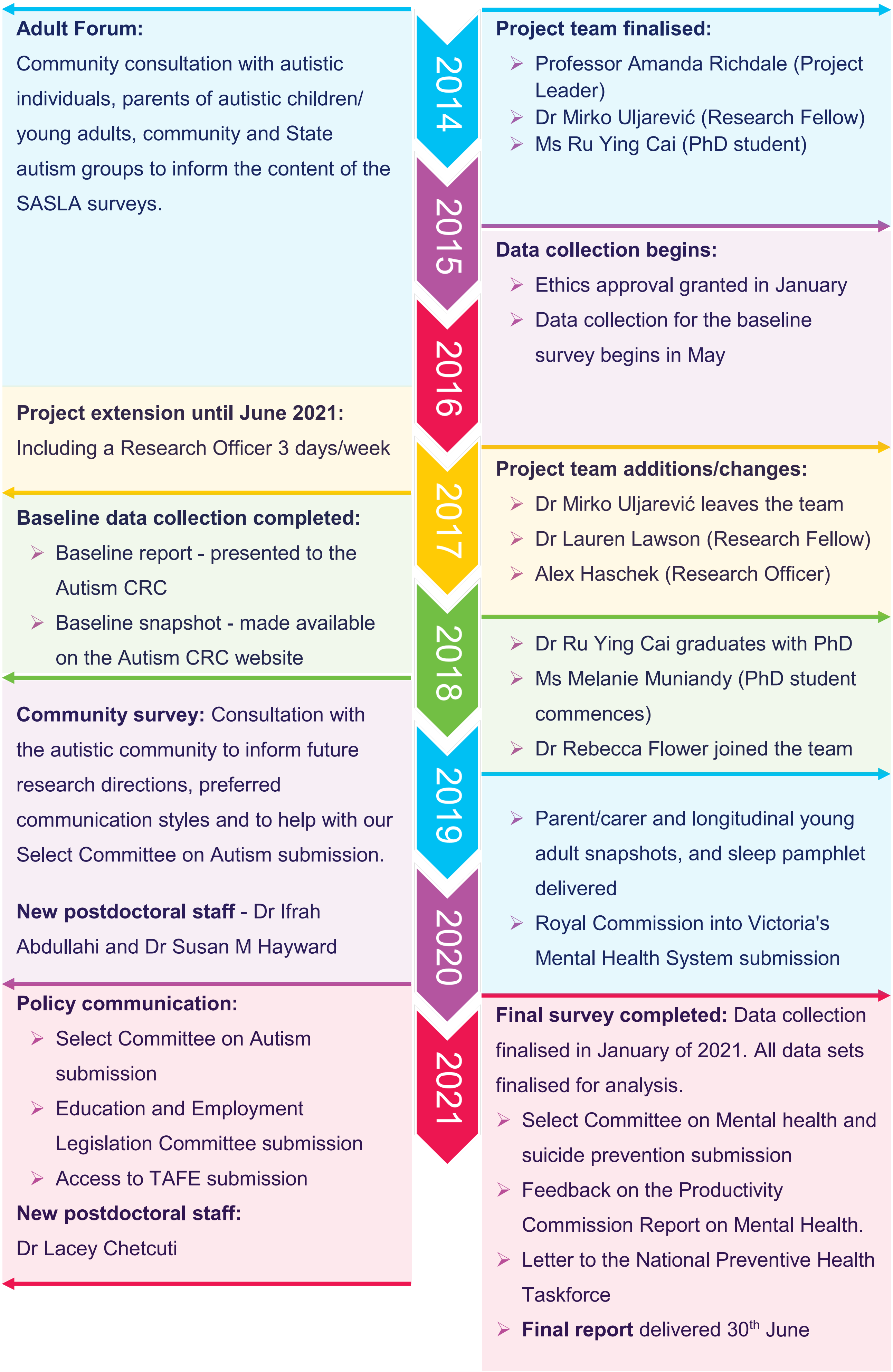
[2] https://www.autismcrc.com.au/our-programs/adulthood

Figure 1: SASLA timeline



Adult Forum:

Community consultation with autistic individuals, parents of autistic children/ young adults, community and State autism groups to inform the content of the SASLA surveys.

Project team finalised:

- Professor Amanda Richdale (Project Leader)
- Dr Mirko Uljarević (Research Fellow)
- Ms Ru Ying Cai (PhD student)

Data collection begins:

- Ethics approval granted in January
- Data collection for the baseline survey begins in May

Project extension until June 2021:

Including a Research Officer 3 days/week

Project team additions/changes:

- Dr Mirko Uljarević leaves the team
- Dr Lauren Lawson (Research Fellow)
- Alex Haschek (Research Officer)

Baseline data collection completed:

- Baseline report - presented to the Autism CRC
- Baseline snapshot - made available on the Autism CRC website

- Dr Ru Ying Cai graduates with PhD
- Ms Melanie Muniandy (PhD student commences)
- Dr Rebecca Flower joined the team

Community survey: Consultation with the autistic community to inform future research directions, preferred communication styles and to help with our Select Committee on Autism submission.

New postdoctoral staff - Dr Ifrah Abdullahi and Dr Susan M Hayward

- Parent/carer and longitudinal young adult snapshots, and sleep pamphlet delivered
- Royal Commission into Victoria's Mental Health System submission

Policy communication:

- Select Committee on Autism submission
- Education and Employment Legislation Committee submission
- Access to TAFE submission

New postdoctoral staff:

Dr Lacey Chetcuti

Final survey completed: Data collection finalised in January of 2021. All data sets finalised for analysis.

- Select Committee on Mental health and suicide prevention submission
- Feedback on the Productivity Commission Report on Mental Health.
- Letter to the National Preventive Health Taskforce
- **Final report** delivered 30th June

In line with the Autism CRC's inclusive research approach, the SASLA team has actively engaged members of the autism community throughout the project. Details of consultation and co-production are detailed in this report in the timeline in Figure 1 and in sections 3.2, and 3.5.

The following are several comments left by the young Australians who took the time to contribute to this important work. SASLA gave autistic young people in Australia a voice and the SASLA team has spent the last 7.5 years ensuring that their voice has been heard by the autism community, the wider Australian community, Australian policy makers and international autism researchers.

> ***"I just want to help others like me and I hope my information will help others. A lot of the questions hit home for me and made me think a lot,***

> ***"a great set of questions." (Autistic participant - baseline survey)***

> ***"This test was wonderful, really made me feel less alone." (Autistic participant - baseline survey)***

> ***"very thorough and diverse questions! fairly interesting to complete." (Non-autistic participant - baseline survey)***

> ***"Thanks for having me participate over the years. I hope my answers have been useful for you all :) Thank you" (Non-autistic participant - 2-year follow up survey)***

2.1 Sample characteristics

The SASLA study collected survey data from four distinct groups (Figure 2). This section describes the baseline characteristics of each group. As responses to the SASLA survey questions were not forced, and not all respondents completed every question, the results described in this report are based on subsets of the SASLA population with available data for measures of interest.

Figure 2: The groups that completed the SASLA surveys.

Autistic (without ID*)	Autistic (with ID*)	Non-autistic	Parent/Carer
•Clinical diagnosis •15-25 years •Self-report •***n* = 115**	•Clinical diagnosis •15-25 years •Carer-report or self-report •***n* = 27**	•No reported ASD diagnosis •15-25 years •Self-report •***n* = 218**	•Of an autistic young adult aged 15- 25 years •Self-report •***n* = 117**

*co-occurring intellectual disability

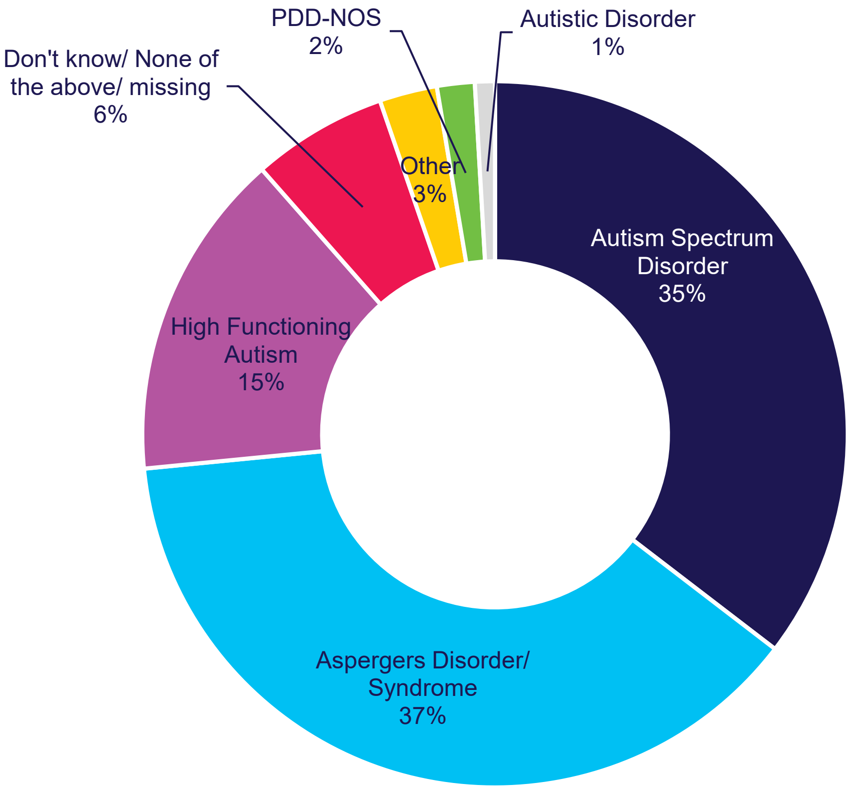
2.1.1 Autistic and non-autistic young adults 15-25 years of age (self-report with no intellectual disability)

2.1.1.1. Autism diagnoses and intervention

Young adults were asked if they had been diagnosed with one of the following: Autism Spectrum Disorder, Autistic Disorder, Asperger's Disorder/Syndrome, High Functioning Autism, or PDD-NOS. A total of 115 participants reported having received an autism related diagnosis (self-report and/or parent/carer-report). The breakdown of diagnostic categories is presented in Figure 3.

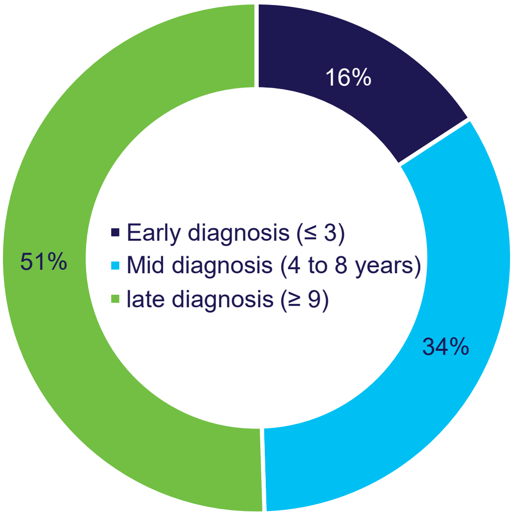
Respondents also were asked to provide information on their age of diagnosis and any supports they received over their lifetime. The average age of diagnosis reported was 9.8 years. Figure 4 illustrates that despite a reasonable proportion of individuals receiving an early diagnosis (i.e., ≤ 3 years), over half the participants in this cohort received their autism diagnosis after the age of 9 years, including three SASLA participants who entered the study as non-autistic participants and subsequently reported an autism diagnosis.

Figure 3: Diagnostic category breakdown of young autistic adults



Most respondents (78%) reported receiving some form of intervention or support for their social and communication difficulties. Twenty six percent reported receiving some form of early intervention and 7% received Applied Behaviour Analysis (ABA). Almost a third of the sample reported having an integration aid at primary school (32%) and/or at high school (30%) and about a third of the sample (34%) reported receiving some other form of support including speech therapy, occupational therapy, psychological intervention, and physiotherapy.

Figure 4: Age at diagnosis for participants with a reported autism related diagnosis



2.1.1.2. Age and gender

Both the autistic and non-autistic samples reflect SASLA's target age range of 15 to 25 years (Table 1), with no significant difference between the age of participants in each group.

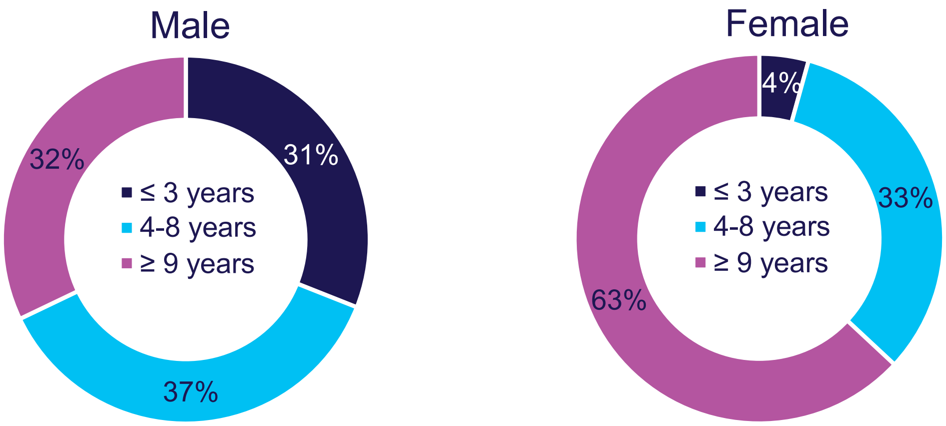
Table 1: Age and gender profile of young adults[3]

	Autistic		Non-autistic	
	Male	Female	Male	Female
***n* (%)**	65 (58%)	47 (43%)	61 (36%)	111 (64%)
Mean Age (years)	18.9	19.0	17.6	18.9
	19.0 years		18.4 years	
Age Range (years)	15-25	15-25	15-24	15-24

The SASLA study has a significantly larger proportion of males to females in the autistic group, and females to males in the non-autistic group. Nevertheless, the male to female ratio in the autistic group is lower than typically reported. These differences likely reflect the diagnostic gender disparity in ASD and tendency for females to engage more in online research.

In this age group, autistic females were being diagnosed later than autistic males. Autistic female participants were significantly less likely than autistic males to be diagnosed at 3 years of age or under and far more likely to be diagnosed at 9 years or older (Figure 5).

Figure 5: Autistic young adults without an ID age of diagnosis by gender



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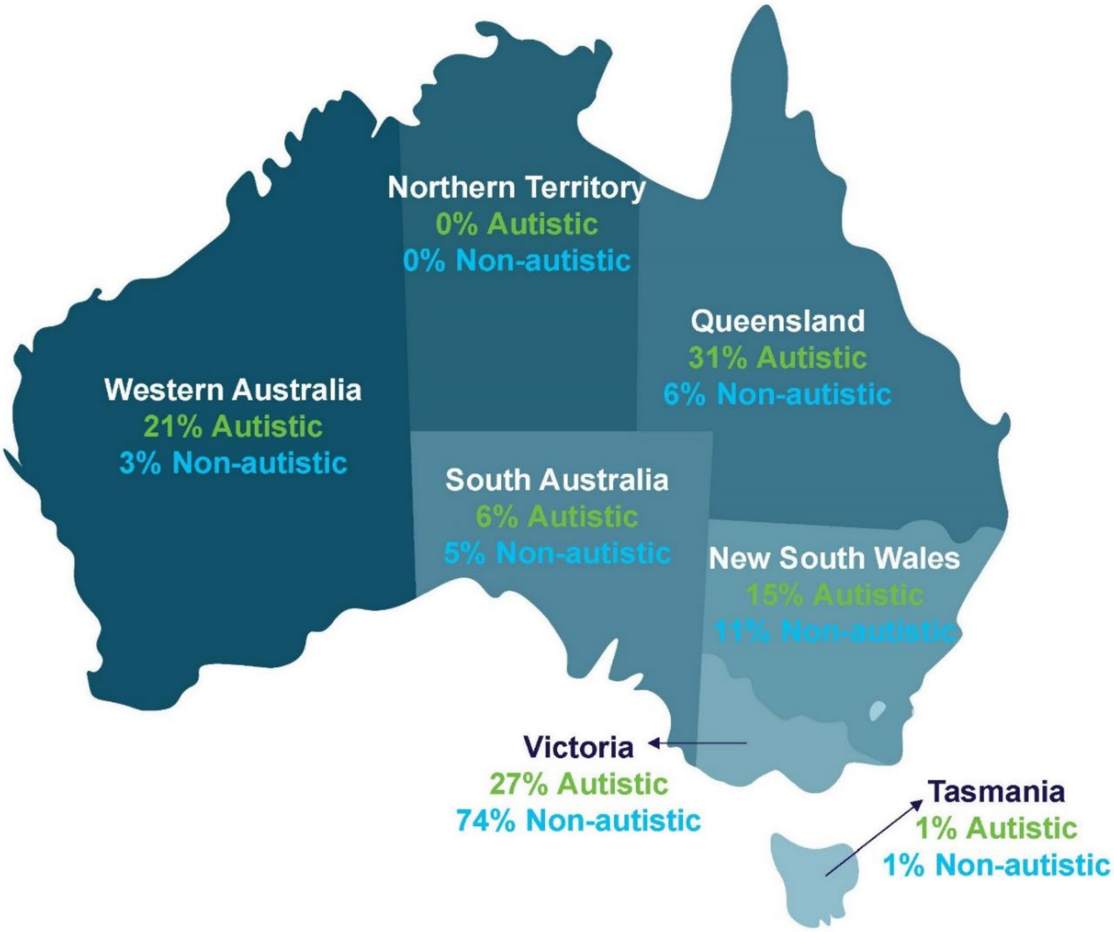
[3] The gender question in the baseline survey was revised in response to feedback from autistic individuals through the OTARC and the ALSAA Advisory Group. The final survey includes a series of questions based on both Australian and International guidelines on the recognition of sex and gender (see Appendix 3).

2.1.1.3. Current location

SASLA participants represent a wide range of locations across Australia (Figure 6). We have autistic individuals represented in all states but not Australian territories. The non-autistic group is slightly more restricted in its representation. This is likely because the most successful recruitment strategies aimed at non-autistic participants were based in Victoria (i.e., Rulo and student networks). Overall, there were significant differences in location between the autistic and non-autistic groups, with:

- more autistic participants from Queensland (31%) and Western Australia (30%), and
- more non-autistic participants from Victoria (74%).

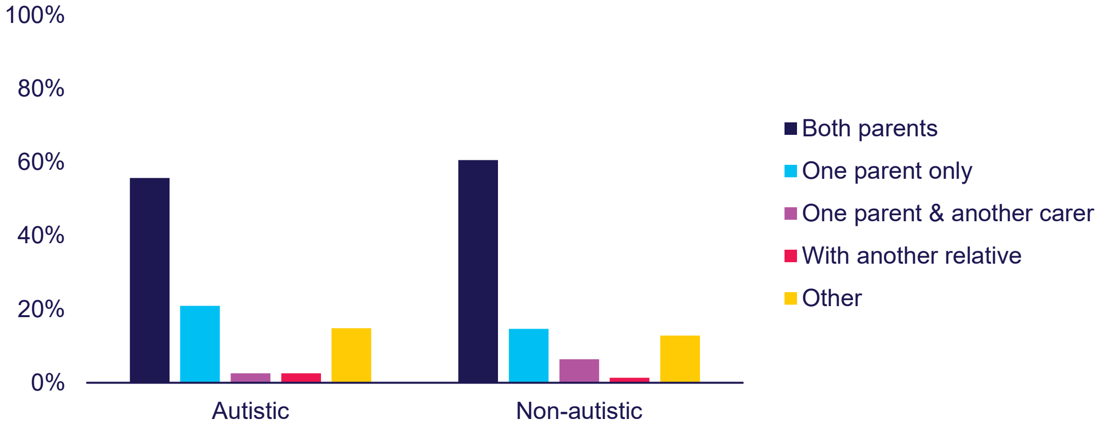
Figure 6: Distribution of young adult participants without an ID by State in Australia



2.1.1.4. Sociodemographic factors

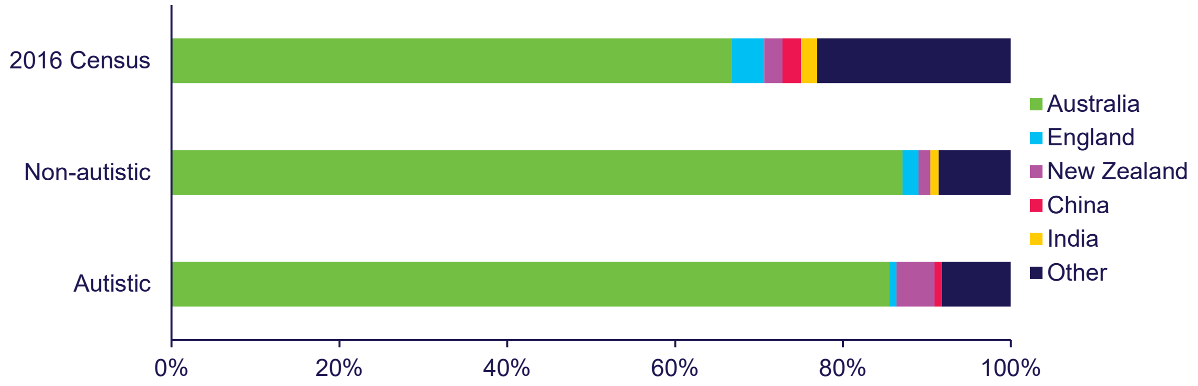
Young adults were asked about their living situation. Most young adults, regardless of diagnostic status, reported living with both parents (Figure 7). For both groups, the second largest proportion reported living with a single parent. Autistic Australians also reported living in university student apartments, with a roommate/share housing, or with a partner. No differences were found across the two groups for living situation.

Figure 7: Living situation of young adult participants



Participants were also asked to provide details about cultural and linguistic background. As expected, the majority (> 85%) of respondents in all groups were born in Australia (Figure 8), which is somewhat higher than in the 2016 Australian census. The remaining participants reported a wide range of countries of birth including New Zealand, China, Malaysia, England, South Africa, Netherlands, and others. In addition, the young adults in SASLA reported a variety of ethnicities, reflective of Australia's unique ethnic composition. Most participants in both groups identified as Australian (autistic = 69%, non-autistic = 75%). Australian Aboriginal and Torres Strait Islanders were slightly underrepresented in the non-autistic sample (2%) however the autistic sample exceeded the 2016 census data (2.8%), with 3.6% of autistic young adults identifying as Aboriginal or Torres Strait Islander. The remaining participants reported other backgrounds including Anglo/Celtic, Asian, Bangladeshi, Chinese, English and many others. No differences were found between the groups for country of birth or ethnicity.

Figure 8: Young adults' self-reported country of birth



Most participants reported speaking English at home (Table 2). However, young people on the spectrum also reported speaking other languages such as Bengali, Cambodian, Indonesian, Italian, Mandarin, Spanish and Tagalog at home. Our autistic young adults were less likely to speak a language other than English at home than their non-autistic peers.

Table 2: Main language spoken at home

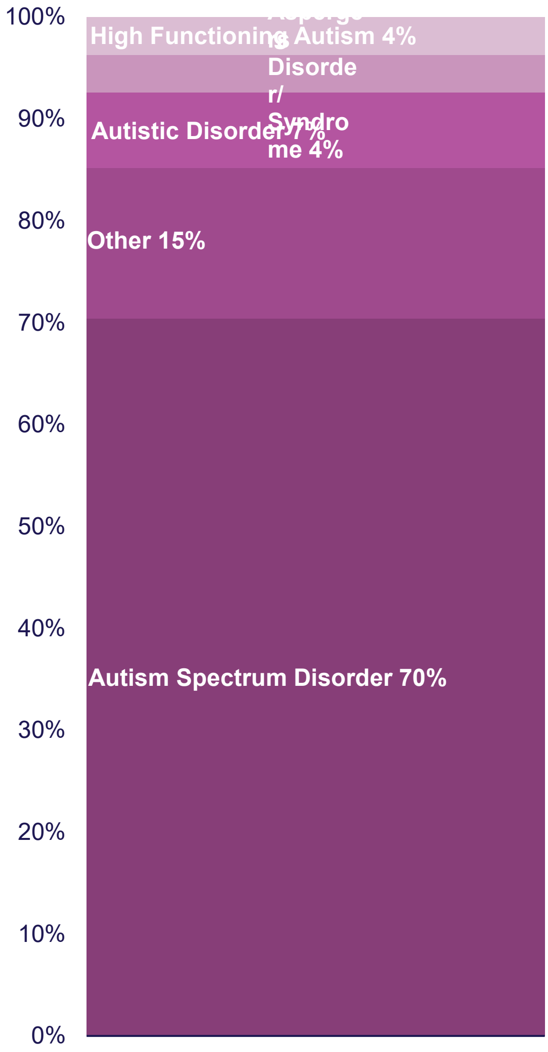
	Autistic	Non-autistic	2016 Census
English only	94.5%	82.7%	72.7%
Mandarin	0.9%	1.4%	2.5%
Arabic	0%	0.5%	1.4%
Cantonese	0%	1.0%	1.2%
Vietnamese	0%	0.5%	1.2%
Other	4.3%	13.9%	21%

2.1.2. Autistic young adults with a co-occurring intellectual disability 15-25 years of age (Caregiver and self-report)

Twenty-seven autistic SASLA participants reported a co-occurring Intellectual Disability (ID) at baseline. Of these, 23 had a parent/carer completed survey and four participants completed the self-report questionnaire.

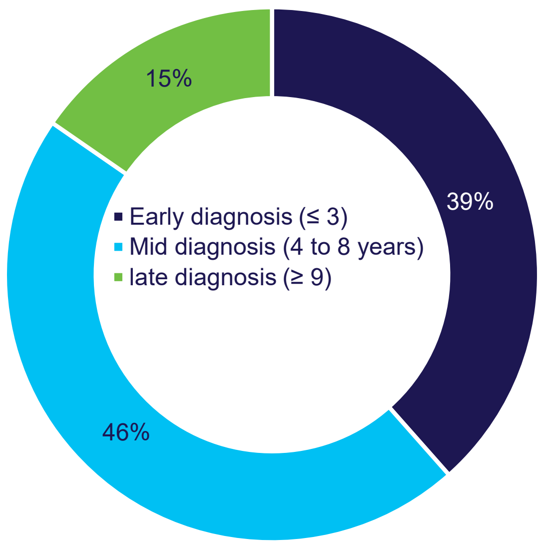
2.1.2.1. Autism diagnoses and intervention

Figure 9: Diagnostic category breakdown for young autistic adults with an ID



Parents/carers/individuals were asked if they/their child had been diagnosed with one of the following: Autism Spectrum Disorder, Autistic Disorder, Asperger's Disorder/Syndrome, High Functioning Autism, or PDD-NOS. None of the 27 young adults had a reported diagnosis of PDD-NOS and all knew their own/their child's diagnosis. The breakdown of diagnostic categories is presented in Figure 9.

Figure 10: Age at diagnosis for young autistic adult respondents with an ID



The average age of diagnosis was 5.8 years. Young autistic adults with an ID were more likely to receive their autism diagnosis early (≤ 3 years of age) and were far less likely to be diagnosed later (≥ 9 years of age) than their peers in the autistic group with no ID. Figure 10 shows a breakdown of age of diagnosis for this group.

Most respondents (92%) reported receiving some form of intervention or support for their social and communication difficulties. Almost 70% received some form of early intervention and 89% received Applied Behaviour Analysis (ABA). 77% reported having an integration aid at primary school, increasing to 92% by high school. Over half the sample also reported receiving other forms of support including speech therapy, occupational therapy, and equine therapy.

2.1.2.2. Age and gender

The age range of this group was 16 to 25 years with male and female participants with no differences in age between male and female participants (Table 3). There were four times as many males to females. This reflects the current diagnostic rate for autism in Australia (Australian Institute of Health and Welfare, 2017).

Table 3: Age and gender profile of young adults with an ID

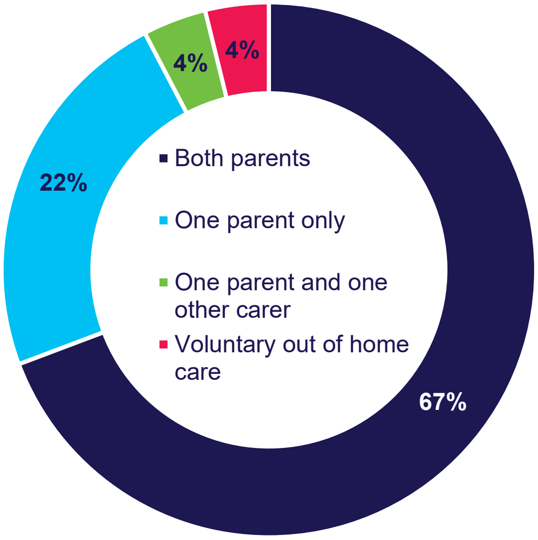
	Male	Female
***n* (%)**	22 (81.5%)	5 (18.5%)
Mean Age (years)	18.1	19.4
	18.4 years	
Age Range (years)	16-22	16-25

2.1.2.3. Current location and Sociodemographic factors

Most young adults in the ID group resided in Queensland (27%), Victoria (33%) and New South Wales (30%) with a small number from Western Australia (11%) and South Australia (7%). All young adults were living in a supported environment (Figure 11). Most were living with both, or one parents or a relative (96%), which was higher than autistic participants without ID (82%) and non-autistic participants (83%).

Most were born in Australia (85%) with the remainder being born in Scotland, Indonesia, Singapore and the Netherlands. Over 70% of participants in this group identified as having an ‘Australian’ ethnic background. Only one participant spoke a language other than English at home.

Figure 11: Living situation of young autistic adults with an ID



2.1.3. Parents/carers of autistic young adults

117 parents/carers of an autistic young adult completed the baseline survey. Of these, 18 were parents/carers of young autistic adults with an ID. We have 88 matched parent/carer and autistic young adult pairs.

2.1.3.1. Age and gender

Mothers were more likely to engage with the project (Table 4) representing over 90% of the parent/carer sample (5 carers did not indicate their gender). This is consistent with previous research. The average age of the sample was 50 years.

Table 4: Age and gender profile of parents/carers of autistic young adults[4]

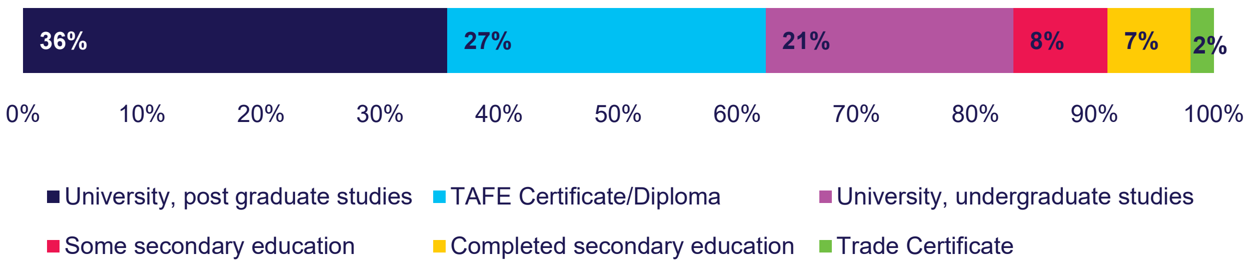
	Male	Female
***n* (%)**	10 (8.9%)	102 (91.1%)
Mean Age (years)	55.0	50.0
	50.4 years	
Age Range (years)	37-72	36-71

2.1.3.2. Current location and Sociodemographic factors

More than 80% of parents/carers of young autistic adults were born in Australia. The remaining parents/carers were born in a variety of countries including England, Hong Kong, Iran, Ireland, Malaysia, Kenya, New Zealand, Philippines, Russia, Scotland, Singapore, South Africa, and Switzerland. Almost all spoke English in the home (99%). Other languages spoken included Tagalog, Farsi, Italian and Mandarin.

The parents/carers who participated in SASLA were highly educated, with more than 85% having completed post-secondary education (Figure 12); 63% had a university degree.

Figure 12: Highest level of education of parents/carers of autistic young adults



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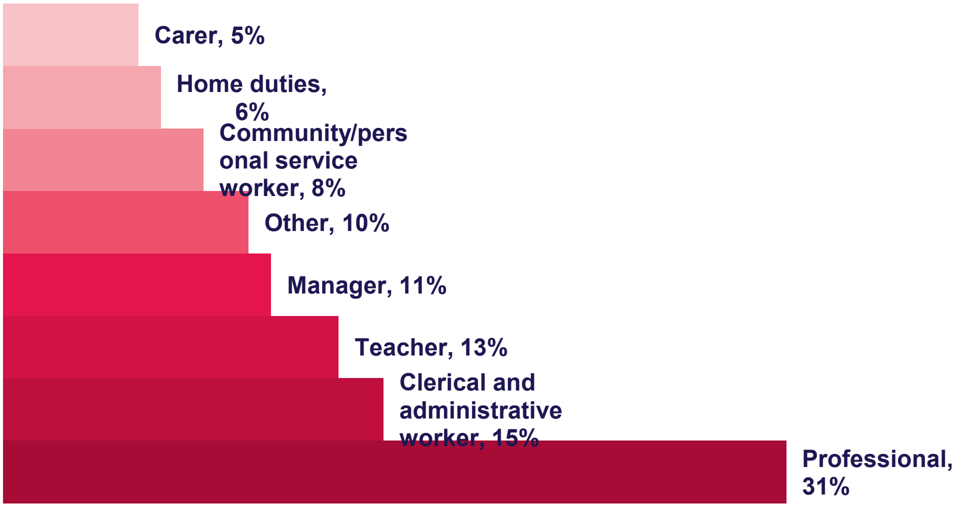
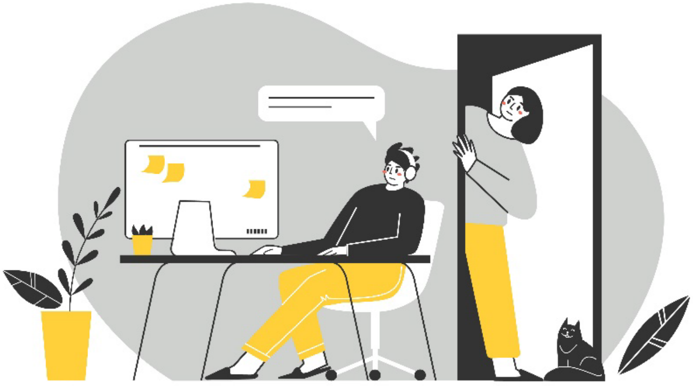
[4] Not all participants provided a date of birth thus *n* = 112.

Most parents/carers were employed at the time of the baseline survey either full time (32%) or part-time (32%). At the time, all parents/carers completed the first survey their unemployment rate was slightly lower than the national average of 5%[5] with only 4% indicating they were currently unemployed. Occupations varied across the sample, with the most common role being a professional, followed by clerical and administrative roles, teaching and management (Figure 13). Approximately 11% were carers or undertaking home duties full-time. The 'other' category included studying, being retired or being a sales worker.

Figure 13: Occupation of parents/carers of autistic young adults





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[5] December 2018, https://www.abs.gov.au/ausstats/abs@.nsf/lookup/6202.0Media%20Release1Dec%202018

3. Research design and methods

SASLA is a longitudinal cohort study where participants were followed for 2 years and completed 3 surveys (see Figure 14). Each survey took approximately 45-60 min to complete (depending on the individual). Cohort studies follow a group of people with a defining characteristic - in this case an autism diagnosis. The cohort design allowed us to observe any differences between the experiences and perceptions of autistic and non-autistic Australians. Having a longitudinal design allowed us to explore causal relationships and change over time. In deciding what questions to ask in these surveys we used the collective experience of the research team, experienced autism researchers, the vision and mission of the Autism CRC[6], and the experiences of autistic individuals, their families and state and community organisations that serve the autistic community.

Figure 14: SASLA survey delivery times

3.1 Aims

- Identify and describe concurrent educational and vocational outcomes, as well as change over time.
- Identify concurrent physical, mental health, and well-being outcomes, as well as change over time.
- Identify predictors, both concurrent and longitudinal, of educational, vocational, health, and well-being outcomes for young people.
- Describe the health and well-being of parents/carers of young autistic Australians and identify risk and resilience factors contributing to such parent/carer.
- Use the survey data collected to validate existing scales for use in young autistic Australians.

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[6] https://www.autismcrc.com.au/

3.2 Community consultation – what questions should we ask?

In October 2014, before formal commencement of the SASLA study, a 2-hour ‘Adult Forum’ was conducted with members of the autism community[7] to gather information about areas of focus that should be addressed by the project. Participants in the forum were invited via autism support organisations (Alpha Autism, AMAZE, Asperger’s Victoria) contact lists, contacts on the OTARC registry as well as individual support workers and OTARC associates (e.g., OTARC advisory committee, psychologists working with adults). The OTARC website also hosted an open registration page for independent contacts. Participants in the Adult Forum completed an anonymous online survey (See Appendix 1) prior to the in-person Forum. The Forum itself consisted of two presenters talking about their experiences (1 autistic individual and 1 parent of an autistic young person) and seven panellists (3 parents, 3 autistic individuals, and 1 support worker) answering several questions (See Appendix 1) around their experiences.

The main areas of interest identified through the Adult Forum and consultation survey were:

- How to cope with stress/anxiety/depression.
- How to help gain and keep employment/career advice.
- How to obtain practical skills-for example driving.
- How to find suitable tutor/support-worker/mentor.
- Adult housing/independence support.
- How to help in making transition from school to employment successful.
- About successful social integration programs.
- Autism and aging.

The team also and held individual meetings with community stakeholders including autistic individuals, Asperger’s Victoria, parents of autistic teens and adults, and I CAN Network. Over the course of the project SASLA has used an informal advisory group to assist with the development of questions used in the SASLA survey and with general advice:

- Penny Robinson
- Max Williams
- Amanda Golding
- Dariane McLean
- Lyndel Kennedy
- Robyn Guild
- Nik Nikoliev
- Tamsin Jowett

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[7] Including autistic people, their families, community groups and service providers.

The outcomes of this consultation informed questions/scales that were included in the final survey (e.g., employment, anxiety, stress, loneliness, environmental factors such as teacher understanding, and autism specific problems including communication, understanding, and socialisation). An advisory group was assembled in 2017, consisting of nine parents/carers and two autistic individuals. The advisory group provided feedback on recruitment materials and strategies for our final recruitment push in 2018.

The SASLA study has continued to consult with autistic individuals and the ALSAA advisory committee on a case-by-case basis on publications, communication of our results to the public, and co-writing peer reviewed publications with autistic researchers over the duration of the project.

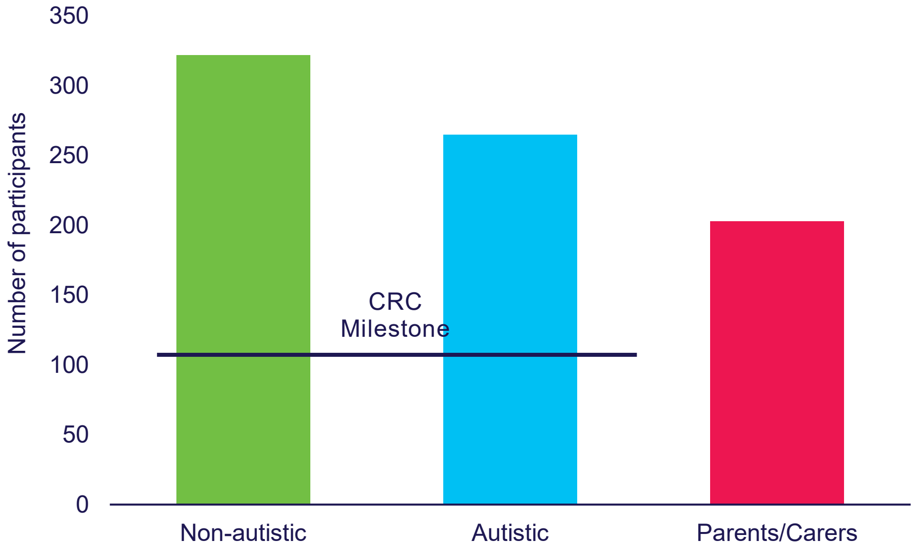
3.3 Data collection

Human research ethics approval was granted in January 2015 (Approval number HEC14-095; La Trobe University Human Research Ethics Committee) with data collection for the baseline survey commencing in May 2015 and recruiting across four populations (Figure 2). Data collection was completed mid-January 2021.

3.3.1 Expressions of interest

Recruitment into the baseline survey continued from commencement of data collection in 2015 until June 2018. Many avenues were used to advertise the study, including social media, engagement with community groups, newsletters, mailing lists, state autism organisations (e.g., Amaze, Autism Queensland) and online research panels (e.g., Rulo).

Figure 15: Numbers of participants who expressed interest in participating in SASLA by group.



Interested participants contacted the project team and were provided with additional information about the study and consent forms (numbers provided in Figure 15). Informed consent was obtained from:

- the individual if they were 18 years of age or above (parents/carers/young adults), or
- the individual *and* the parent/carer if under the age of 18 or if the young adult had a co-occurring intellectual disability and was not completing the self-report survey.

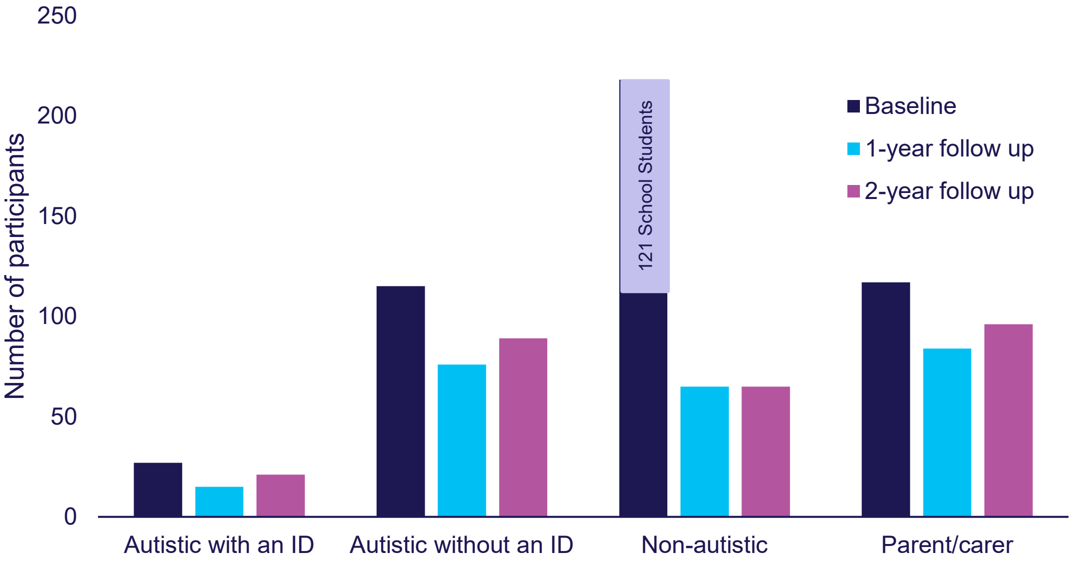
Participants could choose to receive the survey either online or in hard copy and 7 participants received a hard copy via mail. At baseline, due to some initial concerns about potential participant burden, the survey was sent in two consecutive batches, the second being sent after the first was completed. Subsequently this was altered to having all questions in a single survey for both 1- and 2-year follow-up.

3.3.2 Completions

The SASLA study had good participant retention, particularly autistic participants and their parents/carers (Figure 16). Participants had one month to complete the first baseline survey batch and a further month to complete the second batch of questionnaires. They had four months from their due date to complete the 1-year follow-up survey and six months to complete their 2-year follow-up survey; reminders were sent. Of participants who were eligible[8] to complete the 2-year follow-up survey, the majority did so:

- 80% of autistic participants,
- 58% of non-autistic participants, and
- 81% of parent/carer participants.

Figure 16: Frequency of completion of the three SASLA surveys



The non-autistic sample at baseline included a shortened data set from 121 school students. These individuals did not continue to 1- and 2-year follow up surveys as the cooperation of the school was withdrawn.

3.4 Materials

3.4.1 Demographics

The SASLA surveys collected a variety of demographic information (Table 5), as directed by the 'Adult Forum' focus areas and previous research. A full list of demographics questions from the baseline surveys can be found in Appendix 2. This information has been considered in our research examining potential predictors of individual difference outcomes within the sample (See Section 4). Many of the demographics in the SASLA studies overlap with those of the ALSAA

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[8] Participants were classed as ineligible due to lack of contact details (E.g., inactive email, no mailing address) or if they had withdrawn from the study. For further information see Section 3.7.2.

study so that we can use both sets of data and examine changes across the lifespan from mid-adolescence.

Table 5: SASLA survey demographic information collected

Research area	Information captured	Individuals	Parents/carers
Basic demographics	Sex at birth (time 3) and gender (binary in Time 1, extended at time 3), state of residence, living arrangements, language spoken at home, country of birth, ethnic background, highest level of education.	x	x
Diagnosis	Category, year of diagnosis, presence of a diagnostic report, disclosure of diagnosis, preferred terminology and early intervention service history.	x	x
Early intervention history	Type of supports received for social and communication difficulties.	x	x
Transition supports	Types of supports received, satisfaction with supports received, what supports would have benefited your transition.	x	
Study	Year of study, type of study, qualification to be achieved, relationships with students/teachers, bullying, grades, out of school activities.	x	
Employment	Occupation, tasks and duties, job satisfaction, part time/full time, job seeking behaviour.	x	
Supports	Supports received and knowledge of available supports (e.g., career, government funding, health, money, license, friendships).	x	
Medical history	Diagnosed physical and mental health conditions over the lifetime, current conditions, current treatment, medication use, medical checks in last 12 months, multiplex/simplex.	x	x

3.4.2 Questionnaires

The SASLA surveys collected data on the key research areas detailed in Table 6. For each key research focus area, relevant questionnaires were chosen by the researchers for their psychometric properties, their suitability for the population of interest and in relation to the autistic community feedback (e.g., Adult Forum). For a full list of questionnaires included in the SASLA surveys please refer to Appendix 2. Parent/carers completed particular questionnaires about their child (see Appendix 2 – questionnaire list for more detail). Many of the questionnaires in the SASLA studies overlap with those of the ALSAA study so that we can combine both sets of data for analysis and obtain a lifespan perspective from mid-adolescence.

Table 6: SASLA survey content characteristics

Research area	Information captured	Individuals	Parents/carers
Autism Characteristics	Autism traits	x	x
	Repetitive behaviours	x	x
	Sensory	x	x
	Intolerance of uncertainty	x	x
	Diagnosis	x	
Health	Sleep	x	x
	Autonomic symptoms	x	x
	Medical profile	x	x
	Medications	x	x
	Fatigue	x	x
Mental Health	Anxiety	x	x
	Depression	x	x
	OCD	x	x
	Mental well-being	x	x
	Positive affect	x	x
Emotion	Emotion regulation	x	x
	Coping	x	x
	Adult temperament questionnaire	x	x
	Emotional awareness	x	
	Behavioural inhibition	x	x
Activities, Participation & Quality of Life	Quality of life	x	x
	Physical activity	x	x
	Satisfaction with love life	x	x
	Social support	x	x
	Bullying	x	
Cognition & Adaptive Functioning	Supplementary IQ	x	x
	Daily living		x
Caring/Caregiver Activity	Feelings about and from your child		x

3.4.3 Continuous improvement and updates to the surveys

The SASLA team were committed to adapting the follow-up surveys and research outputs using preliminary results of interest, changes in research priorities for the autistic community, and feedback from our participants. This led to the following additions to the 2-year survey:

- Additional open-ended questions regarding **autism terminology** preference were added based on consultation with the autism community, this is an important topic where more information was required.

> ***1. What are your preferred way(s) to describe people on the autism spectrum?***
> ***2. What is your preferred term for people to describe you?***
> ***3. Do you have any other comments on language used to describe people on the autism spectrum?***

- A series of questions about **disclosure of diagnosis**. The inclusion of these question gains additional information about the individual's perceived benefits or disadvantages of disclosing their diagnosis.
- The original **gender** question (male and female only) was extended to a non-binary option based on feedback from the autism community on national (Australian Government, 2013) and international guidelines. See Appendix 3 for question wording.
- The **Impact of Diagnosis** Scale (Courtney et al., 2016) was added as it was identified as an area of interest within the autism community and had not yet been measured by self-report among adults. As such with consultation with the original authors, we developed a revised version of the IODS (IODS-R) for use with autistic adults (See Section 4.4.2).
- The Retrospective **Bullying** Questionnaire (Rivers, 2001) was added after demographic questions revealed high levels of bulling in both groups.
- The Satisfaction with **Love Life** Scale (Neto, 2005) was added due to feedback related to relationship satisfaction from participants and advisors.
- The International **Physical Activity** Questionnaire – Short Form (IPAQ; Booth, 2000) was added given physical activity has been associated with sleep and mental health difficulties (Penedo et al., 2005).

- The **Communication** Checklist – Adult (Whitehouse et al., 2009) was added to gather information about communication challenges experienced by participants.

- Questions about **familial autism history** were added as mounting evidence suggests that there may be behavioural and cognitive differences between individuals with simplex autism (i.e., no family members with a diagnosis) and multiplex autism (i.e., multiple first-degree relatives with a diagnosis). This survey was also sent to participants who had already completed all three surveys and their information added to the data set.

- A measure of **COVID19** impact was added in April of 2020 (see Appendix 4 for the questions). The results on this additional questionnaire are summarised in Section 4.5.

- The Brief Cope (Carver, 1997) was introduced to study **coping strategies** over time. This was the initiative of PhD student Melanie Muniandy for her research. The survey was also sent to participants who had already completed all three surveys and responses added to the data set.

- The Developmental Behaviour Checklist (Mohr et al, 2011) was included to gather information about the young adult's **behavioural and emotional difficulties** as rated by their parents.

3.5 Co-production

In 2019, the SASLA team were approached by a La Trobe university placement officer within the Department of Public Health to ask if we could supervise an autistic 4th year placement student, Josh Vartuli. Josh helped us with a peer-reviewed journal submission and is a co-author (Lawson et al, 2020). Josh offered valuable insights and perspectives to the team. Josh is now a consultant with SASLA and can offer ongoing, valuable feedback on the results of our publications. To read more about Josh's time with SASLA please see Section 5.3.5.

In 2020 Dr Susan M Hayward joined the SASLA team one day per week. Susan provided an important perspective to three policy submissions, clinical fact sheets and in the crafting of research questions. Susan's research interests include employment and social inclusion of individuals on the autism spectrum, and their psychological health and well-being. You can read more about Susan in Section 5.3.1.

3.6 Updating research priorities

As the SASLA project continued to collect data (from 2015), we produced user identified resources (full list is available in Section 5.1.4). In January 2020, a survey was sent to the SASLA newsletter subscribers (386 contacts) – consisting of autistic individuals aged 17–27 years, their parents/carers, members of autism specific organisations and individuals who work with autistic people - to help us determine:

1. Future research directions for the use of SASLA's longitudinal data,
2. Preferred methods of science communication, and
3. Which terms of reference determined for the Select Committee on Autism[9] were most important to our SASLA community.

See Figure 17 for a breakdown of the sample.

Figure 17: Profile of participants of the research direction survey January 2020.

Participants were asked to place seven areas of research covered by the SASLA study surveys in their order of importance. The results are presented in Figure 18.

Figure 18: Areas of research in order of importance by the SASLA community

1	• **Mental health** (e.g., depression, mental well-being)
2	• **Temperament and emotional regulation** (e.g., coping)
3	• **Health** (e.g., Sleep, medical profile, medication use)
4	• **Activities, participation and quality of life**
5	• **Cognitive and adaptive functioning** (e.g., daily living)
6	• **Autism characteristics** (e.g., repetitive behaviours)
7	• **Carers** (e.g., carer supports and coping)

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[9] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism

We also asked our community how they were currently gaining information about the SASLA study findings. The most reported modes of communication were the quarterly SASLA newsletter and videos (See Section 5.1.3 for further information). The OTARC Facebook page, presentations and research articles were also used as sources of information for the SASLA community. When asked about the best way to communicate our findings, a word frequency analysis revealed that videos, emails and social media were preferred (Figure 19). We built our 2020-2021 communications strategy around this feedback.

Figure 19: Word cloud for the question *"How could we make our research findings more available to the autistic community and wider society?"*

3.7 Limitations

Below we describe our challenges in recruitment, retention, consultation, and data quality and how we improved our systems, protocols and communication strategies to reduce their impact on the quality of our research.

3.7.1 Participant numbers

The SASLA study met many barriers to recruitment of participants in its early stages partially due to the age-group targeted and the significant commitment required (2 years, 3 surveys). Our PhD student at the time, Ru Cai, and post-doctoral Research Fellow, Dr Mirko Uljarević, did an amazing job recruiting autistic participants but non-autistic participants in particular were difficult to recruit. In 2017, SASLA was funded to employ a Research Officer to support the project, received funds to provide vouchers to thank participants on completion of the 2-year survey, and took on two honours students to help with recruitment, particularly of non-autistic participants. To increase recruitment and retention the SASLA team:

- Offered a $30 voucher at completion of the 24-month survey.
- SASLA honours students assist with participant recruitment, resulting in an additional 13 autistic and 71 non-autistic participants.
- Increased attendance at community events (e.g., Different Journeys social dinners and education seminars).
- Gave further community talks and poster presentations (e.g., SHEDN, La Trobe University open day, OTARC regional seminar)

3.7.2 Retention - withdrawals, bounced emails and ‘opt outs’

Over the course of the project, we had 1 school and 50 individuals discontinue the study (Figure 20). Participants who formally withdrew reported changes to personal or family circumstances, health, and discontinuation of study as their reasons for doing so. Further to these withdrawals, email invitations to the surveys offered the opportunity to ‘opt out’ of receiving emails for that survey. Two autistic, 11 non-autistic, and 1 parent/carer participant(s) opted out of the 2-year follow-up survey.

Figure 20: Frequency and cause of participant withdrawal

1 school (*n* = 121) withdrew after baseline

6 individuals formally withdrew via form

14 individuals opted out of e-mail survey invitations

30 individuals 'lost contact'

As is the case with many longitudinal studies, the SASLA study had difficulty maintaining accurate contact details for some participants. In total, 30 participants had emails that bounced at either 1- or 2-year follow-ups.

To improve retention in the study we:

- Produced a quarterly newsletter (See Section 5.1.3 for further detail) which had an open rate above industry average and a click rate almost 3 x the industry average. This retained a community feeling for participants. The newsletter promoted exceedingly good engagement.

- Changed contact information at baseline to include dual contact details (early 2018).

- Participants whose emails were bouncing were contacted by text message or by mailing address for re-engagement where those details were also available.

These measures improved retention between the 1-year and 2-year surveys by 14% for autistic participants and by 7% for parents/carers.

3.7.3 SASLA consultation/advisory group

The SASLA team spent considerable time and effort to establish a paid formal advisory group but, we met with many barriers when attempting to do so and were not successful. However, the SASLA team did engage an unpaid group briefly to inform our final push for participant recruitment in 2018 and engaged autistic advisors on an ad hoc basis in addition to extensive consultation during the project. Barriers to a formal advisory group included:

- We were unable to obtain funding to compensate members for their time.

- Difficulty attracting a representative number of autistic adults when we asked for expressions of interest, perhaps due to our targeting younger adults as the SASLA is a transition years project.

- Had an over-representation of parents expressing interest in 2018, perhaps due to the SASLA age-group where most young people are still living at home.

It may be that the SASLA age-group already has a large commitment to study, employment and the challenges faced with transitioning to adulthood and therefore could not commit time to an advisory group. This seems consistent with our difficulty in recruiting this age-group into the SASLA longitudinal study overall.

3.7.4 Missing data

As with many longitudinal studies, missing data were an issue. This likely occurred due to the length of the survey (i.e., respondent burden), because answers were not forced (i.e., questions could be accidentally or intentionally skipped), and because we relied initially on manual survey invitations and reminders. Missing data were handled on a variable-by-variable basis; some scales required completion of all questions for a total score to be calculated, while for others there was a permissible percentage of missing questions, potentially allowing imputation of the missing scores. The issue of missing data was promptly addressed by automating survey invitations and reminders in the second half of 2017, and by having the Research Officer (from September 2017) check each survey for missing data immediately upon receipt and follow-up with these participants. Autistic participants were more likely to respond to a request for missing data then their non-autistic peers. Missing data were of greatest concern at baseline, but this decreased over the course of the study.

4. Findings

Section 4 is a summary of peer-reviewed publications (listed in Appendix 5) and unpublished work of Honours, Masters and PhD students which provide important information relating to the aims of the SASLA study.

4.1 Vocation and education

Employment can offer a means of empowering autistic adults to become more active and engaged within their communities, with potential to improve their own outcomes as well as to contribute to the broader Australian community. The employment rate for autistic people in Australia is estimated to be only 27% which is much lower than for individuals with other disabilities (53%) or those without a disability (84%; ABS, 2018).

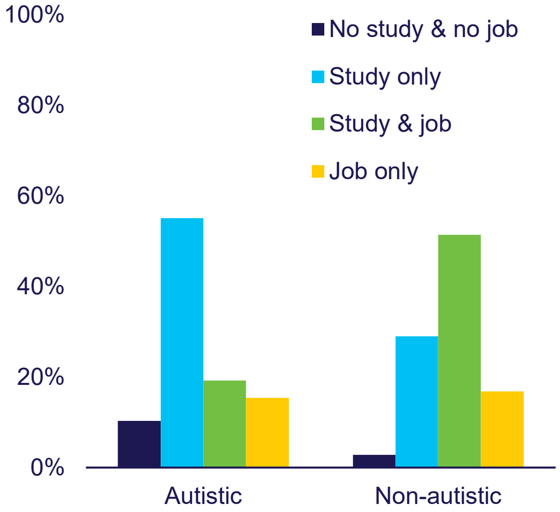
4.1.1 Cross-sectional

4.1.1.1 Post school activities

Compared to their non-autistic peers, young autistic adults were (Flower et al, 2020; Figure 21):

- Just as likely to attend and complete higher education.
- If employed only, likely to be working fewer hours.
- More likely to attend technical and further education (TAFE) than university,
- More likely to enrol in higher education on a part-time basis.
- Less likely to be engaged in both higher education and employment, than their non-autistic peers.
- Less likely to be both employed and in higher education, but if they were employed worked similar hours.

Figure 21: Percentage of young adults participating in post-school activities.



These findings highlight a need to understand post-school trajectories of young autistic adults. Given a similar number in each group reported engaging in higher education, it is important that all higher education providers, not just universities (which tend to be the focus of current research), are knowledgeable about autism and understand how to provide appropriate supports that may assist autistic students.

4.1.1.2 Vocational independence

Vocational independence is the degree to which individuals function independently in postsecondary settings, such as postsecondary education, employment (supported, sheltered, or unsupported), or volunteering (Taylor et al., 2012). So, what is associated with vocational independence? Autistic SASLA participants had high levels of VI (*n* = 69, *M* = 7.7 out of a possible 9, *SD* = 2.6). Lower vocational independence was **not** associated with poor mental health or sleep. Individuals with lower vocational independence did **not** tend to have:

- More severe symptoms of sleep problems, depression, or anxiety.
- Scores above clinical cut-offs for sleep problems, depression, or anxiety.
- Scores above clinical cut-offs for more than one of the following - sleep problems, depression, or anxiety.

This was an interesting finding as it did not replicate past research. It may be that our smaller sample size did not pick up trends reported in other larger studies.

4.1.1.3 Bullying

Bullying was very commonly reported by Australian youth, with 58% of autistic youth without an ID, 50% of autistic youth with an ID and 44% of non-autistic participants reporting having been bullied or picked on at school. From our survey, teasing was the most common form of bullying. Two-thirds of autistic youth had been teased or called names at school. Autistic youth also reported having "*Had things stolen from a locker, desk, or other places at school*" (40%). Of particular concern is the rate of physical attacks or fighting involvement reported by our participants (Figure 22). Autistic youth with an ID were significantly more likely to be physically attacked or involved in fights at school (or to and from school) than autistic youth without an ID or non-autistic youth.

Figure 22: Rates of physical attack or involvement in fights at, to, or from school by young Australians

We also asked our participants how they coped with bullying at school. Young Australian adults were unlikely to seek help from friends with 15% or less doing so (autistic = 12%; autistic with ID = 5%; non-autistic = 15%). Autistic young adults without an ID were more likely to get help from family/parents (28%) compared to non-autistic (18%) and autistic participants with an ID (19%). Only 20% of young adults (across the three groups) in the study sought help for bullying from a teacher. Data from our 2-year (Time 3) bullying questionnaire has not been analysed at the time of this report.

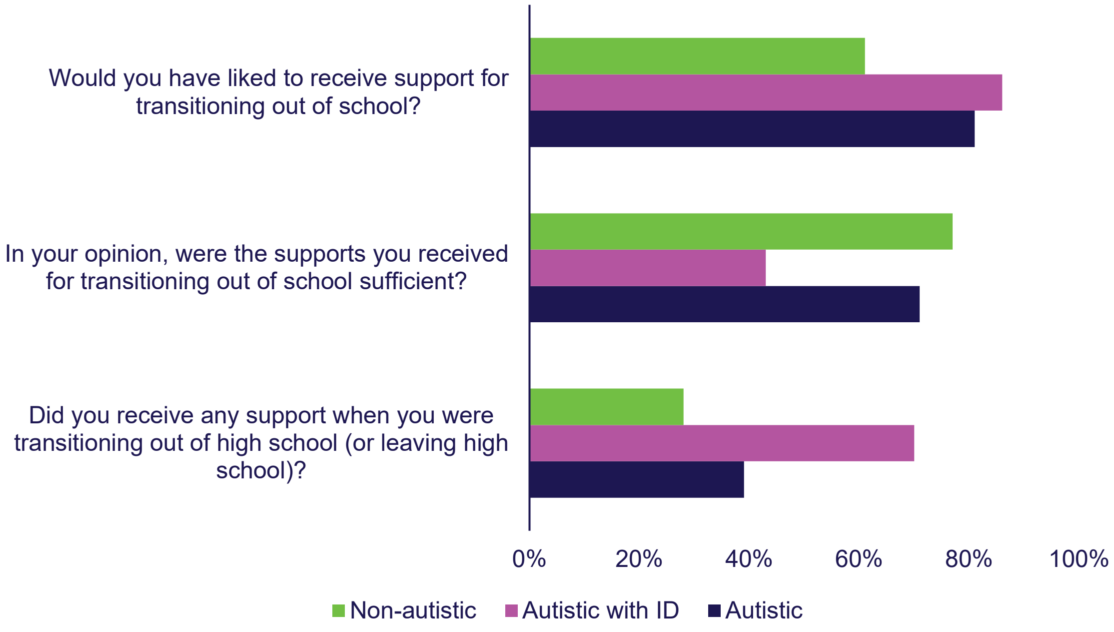
4.1.1.4 Transition supports

We asked a series of questions about transition supports for those young adults who had transitioned out of high school. Supports for autistic young people (with and without an ID) transitioning from high school included:

- Youth allowance
- Work experience
- Support worker who sits in on college classes
- Therapy-focus trips to university,
- Life skills courses
- Independent living skill courses
- Social support from friends and family
- School councillor advice
- TAFE Tasters
- Volunteering
- Equity and Diversity offices on university campuses

Figure 23 summarises our demographic data on transition supports. Our autistic participants (with an ID) were the most likely to have received transition supports (70%) however less than half reported that the supports they received were sufficient (43%). Only 39% of our autistic participants with no ID reported receiving transition supports and most of them considered the supports sufficient (71%). The non-autistic group were least likely to receive transition supports (28%) with 77% believing they were sufficient.

Figure 23: Percentage of participants answering 'yes' to transition support questions



Most participants from all groups (> 60%) would have liked to have more supports available. When we asked what types of supports would be useful our participants said:

> ***"Therapy to cope with the jarring changes, to help me become my own person and not mindlessly chameleon my way around, speech pathology for social skills and general social advice, some kind of careers counsellor or someone in a careers field to not only ecourage (sic) and support pursuing my interests but also advise on how to approach social situations and navigating my disability at work and my rights" (autistic respondent)***

> ***"Some sort of program to go to in order to give me somewhere to socialise and be in a learning space while guiding me to what might be most suitable for me, with accommodations" (Autistic respondent)***

> ***"mentoring?, being shown the campus and what is expected of me day to day, help finding groups/friends that are relevant to my interests" (Autistic respondent)***

> ***"Career Planning, Courses for a Trade, Help with getting a job" (Autistic respondent)***

> ***"With the whole transition process. During the xmas break after i left school and during the first year of being in an adult day program" (Parent report - autistic with an ID)***

> ***"Anything would have been nice. I was very overlooked" (Autistic respondent)***

4.1.2 Longitudinal change

Preliminary investigations into trends over time for activities post-school (i.e., studying, working, both studying and working or no activity) undertaken in 2019 for those autistic individuals who had completed school (Table 7) showed that:

- Most participants were engaged in study at baseline and/or 2 years later, with few participants in the other categories (12 or less).
- A little under half of participants who reported they were not working or studying at baseline were not working or studying 2 years later.
- There was a nearly 50% reduction in the number of participants who reported studying only from baseline to 2 years later.
- Majority of participants who reported work at baseline were still employed 2-years later.
- No significant change over time for study participation, with a third studying at both baseline and 2 years later.

Table 7: A summary of longitudinal change in post high school activity for autistic participants without an ID

Note: (number of participants)

		Time 1			
		No activity	**Study only**	**Employed only**	**Studying and Employed**
Time 3	**No activity**	40%	24%	14%	17%
	Study only	20%	49%	0%	33%
	Employed only	20%	11%	86%	25%
	Studying and employed	20%	16%	0%	25%

4.2 Physical and mental health and well-being

Many of SASLA's publications have focused on the health and wellbeing of Australian autistic adolescents and young adults, and when combined with participants from ALSAA, autistic adolescents and adults through to old age. We have examined anxiety, depression, factors associated with physical and mental health conditions, resilience and coping, sleep, quality of life, loneliness and suicidal ideation.

4.2.1 Prevalence

As outlined in Section 3.4.1 SASLA asked about people's medical history. Table 8 summarises the responses to "*What conditions do you currently have?*". Consistent with high rates of anxiety reported in the research literature, anxiety was reported by a half to two-thirds of autistic young adults, with and without ID, compared to around one-third of non-autistic young adults across the three time-points. Depression was reported by a third or more of autistic adults at each time point and similar numbers of non-autistic young adults at 1- and 2-year follow-up. ADHD was reported by about one-quarter of autistic adults, with and without ID, compared to around 1 in 20 non-autistic adults.

Table 8: Percentage of respondents reporting a current mental or physical health condition at each time point

	Autistic with ID			Autistic			Non-autistic		
	T1	**T2**	**T3**	**T1**	**T2**	**T3**	**T1**	**T2**	**T3**
Anxiety	41%	67%	62%	52%	59%	66%	23%	34%	42%
Depression	7%	13%	5%	30%	36%	43%	16%	32%	37%
Speech or language impairment	48%	27%	33%	10%	7%	10%	0%	1%	2%
Attention Deficit Hyperactivity Disorder	15%	20%	29%	20%	26%	21%	1%	6%	6%
Cerebral Palsy	0%	0%	0%	2%	1%	1%	1%	0%	2%
Allergy	19%	13%	29%	19%	21%	14%	9%	11%	12%
Asthma	4%	7%	0%	15%	13%	12%	12%	15%	19%
Hearing impairment	4%	0%	5%	2%	5%	3%	3%	0%	2%
Visual impairment	7%	0%	5%	10%	5%	10%	4%	2%	3%
Seizure Disorder	19%	33%	24%	3%	3%	2%	1%	0%	0%
Tuberous sclerosis	0%	0%	0%	1%	0%	0%	0%	0%	0%
Other	30%	27%	24%	25%	21%	15%	5%	17%	20%

Sleep problems were prevalent across all groups with around half or more of all participants having poor sleep quality across time (Section 4.2.4) but no participants reported a diagnosed sleep disorder (e.g., insomnia, sleep apnoea). Both speech/language impairment and seizure disorder were most common in autistic adults with ID (around one-third) with only a small proportion of autistic and non-autistic young adults reporting these conditions. Allergies were present in more than 10% of each group at all but one time point, being most common for autistic adults with ID, while asthma was present in more than 10% of autistic and non-autistic young adults but less than 10% of autistic participants with an ID. Cerebral palsy, hearing impairment, visual impairment, and tuberous sclerosis were least commonly reported across the participant groups.

A range of "other" conditions were reported by autistic participants without an ID including 15q13.3 microdeletion syndrome, arthritis, auditory processing disorder, bipolar disorder (II), post-traumatic stress disorder, borderline personality disorder, gender dysphoria, dyslexia, Duanes Syndrome, Ehlers Danlos iii, thrombocytopenia, leukopenia, hypotonia, Elhers-Danlos Syndrome, fibromyalgia, flat feet and psoriasis, low iron, Raynaud's phenomenon, scoliosis, musculoskeletal weakness, non-verbal learning disability, psychotic illness not otherwise specified (mild psychosis), psychosis, selective eating disorder, selective mutism and dyspraxia, sensory issues, sensory processing disorder, prosopagnosia, slow transit constipation and systemic lupus erythematosus.

4.2.1.1 Mental health medication use

Participants without an ID were asked about any medication taken in the past 2-weeks (Table 9). Significantly more autistic participants without ID were taking medication 'for anxiety/nerves', 'antidepressants', 'mood stabilisers', or 'other medications for mental health'. The most common sleeping medication was Melatonin in both groups and Selective Serotonin Re-uptake Inhibitors (SSRIs) were most commonly reported for 'anxiety/nerves', and as 'antidepressants' and 'mood stabilisers'. Twice as many autistic participants were taking antidepressants. A significantly higher proportion of autistic compared to non-autistic individuals were taking any medication however, the proportion of individuals taking two or more medications did not differ significantly across groups.

Table 9: Current mental health medications reported at baseline

	Autistic	Non-autistic
Sleeping tablets	12%	6%
Anxiety or nerves	25%	4%
Tranquilisers	3%	0%
Antidepressants	29%	14%
Mood stabilisers	13%	2%
Other medications	22%	2%

4.2.1.2 Heath checks

At each time point we asked participants about their health check-ups in the last 12 months (summarised in Table 10). Autistic young adults with no ID tended to see the dentist more often than other groups, and while health check-ups or GP visits were consistently high in the autistic individuals with no ID, they decreased markedly for autistic participants with ID and increased markedly for non-autistic participants at 1- and 2-year follow-ups.

At baseline we also asked weight and height and calculated participants' Body Mass Index (BMI). Significantly more autistic participants without an ID were categorised as overweight at baseline compared with non-autistic participants.

Table 10: Proportion of participants reporting health check-ups over three years.

	Autistic with ID			Autistic			Non-autistic		
	T1	**T2**	**T3**	**T1**	**T2**	**T3**	**T1**	**T2**	**T3**
Dentist	56%	27%	10%	65%	71%	67%	30.3%	45%	55%
General health check-up with doctor or GP	78%	27%	10%	60%	66%	72%	37%	71%	80%
Blood test	22%	13%	5%	41%	42%	42%	29%	52%	57%
Cholesterol test	4%	0%	5%	8%	7%	10%	4%	9%	11%
Other check-ups and tests	30%	13%	5%	18%	17%	11%	6%	5%	8%

4.2.1.3 Anxiety and Depression

As shown in Table 8, anxiety and depression are very prevalent in autistic Australians. Our research using SASLA and ALSAA data additionally found that:

- Autistic adults are more likely to reach clinical cut-offs for depression or anxiety[10] compared to the general population (Figure 24; Uljarević, et al., 2020).
- Clinical levels of co-occurring anxiety and depression symptomatology were common in autistic Australians from adolescence to old age (Figure 25; Uljarević, et al., 2020).

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[10] SASLA & ALSAA data; Depression measured with PHQ-9, Anxiety measured using DSM5-GAD.

Figure 24: Depression and anxiety prevalence rates for an Australian autistic and general population sample -[2007 National Survey of Mental Health and Wellbeing highlights)](#)

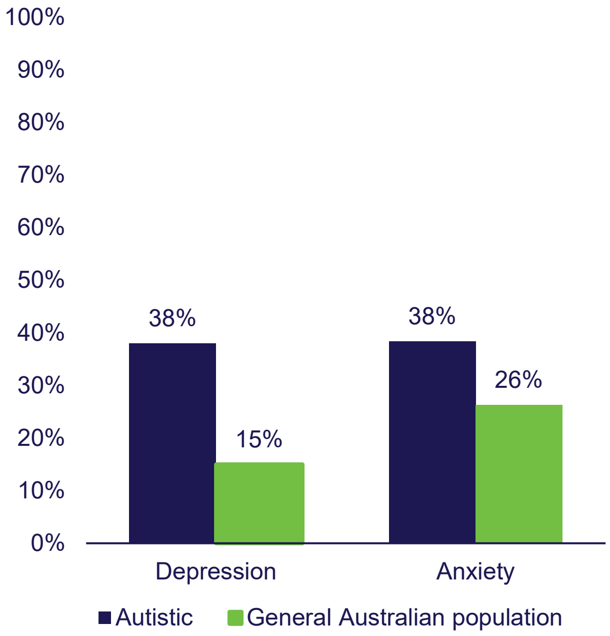
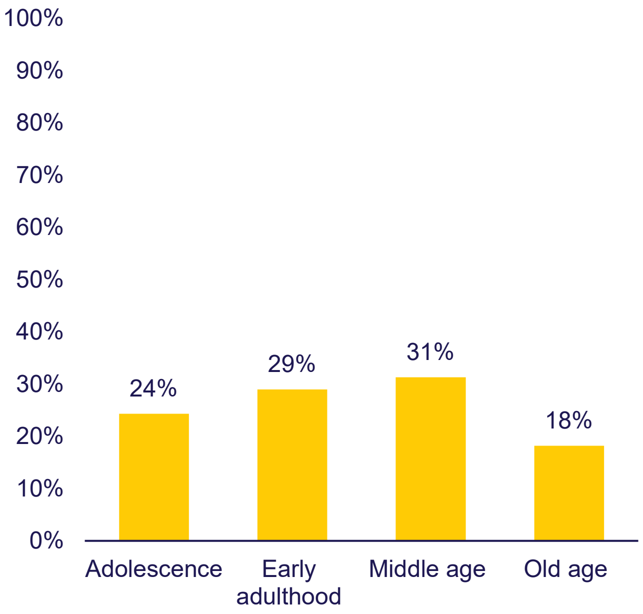
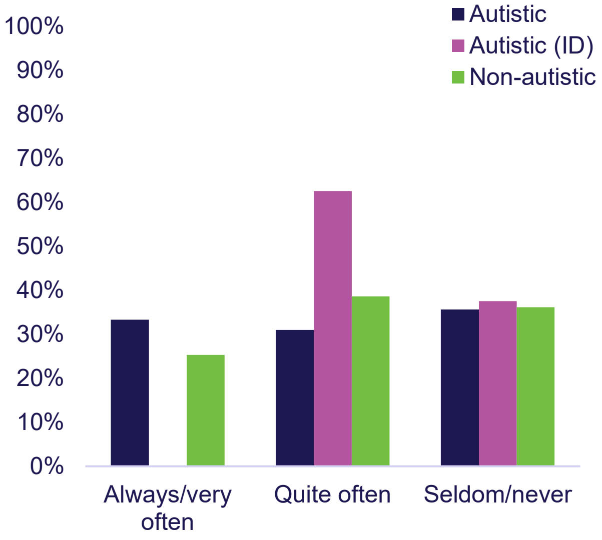


Figure 25: Proportion of autistic Australians meeting clinical cut-off for both anxiety and depression across the lifespan



All groups in the SASLA study also experienced “negative feelings, such as blue mood, despair, anxiety, depression” a significant proportion of the time at baseline (Figure 26).

Figure 26: Percentage of SASLA participants frequency of negative feelings.



4.2.1.4 Exploratory longitudinal outcomes: The Hospital Anxiety and Depression Scale (HADS)

Table 11: Means and range of scores on the Hospital Anxiety and Depression Scale (HADS) across time for SASLA youth

Note: bolded items indicate the mean sample score is above clinical cut-off

Scale	Group	T1	T2	T3
Depression	**Autistic**	5.8 0-16	5.1 0-16	5.3 0-14
	Autistic with ID	4.4 0-13	4.3 (4.7) 0-13	5.4 0-14
	Non-autistic	5.7 0-17	5.4 0-17	6.2 0-19
Anxiety	**Autistic**	**9.2** 0-20	**9.0** 0-19	**8.6** 0-17
	Autistic with ID	**9.5** 3-17	7.3 0-14	**8.3** 1-18
	Non-autistic	**8.7** 1-19	**8.4** 1-19	**8.6** 1-20

The HADS (Zigmond et al., 1983) asks people how they have been feeling over past week, measuring the extent of depression and anxiety symptoms. We found that for participants with complete responses across the three surveys all groups experienced similar levels of anxiety and depression symptoms with no significant change in average symptoms reported over time (Table 11). Mean depression scores were in the normal range for all groups. Levels of anxiety exceeded the clinical cut-off for risk of an anxiety disorder at all time points for all groups except autistic individuals with ID at 1-year who were categorised as borderline.

The HADS also allows people to be placed into three categories: ‘normal’, ‘borderline’, and ‘abnormal’ symptoms. Borderline and abnormal are clinical ‘cases’ that may require supports and may meet criteria for a clinical diagnosis. The autistic group with no ID and the non-autistic groups had around 30% of participants classified above the normal range for depression and all groups had from a third to over 60% of participants classified as above the normal range for anxiety across time. Table 12 provides a summary of the proportion of each group considered a potential ‘case’ at each time point.

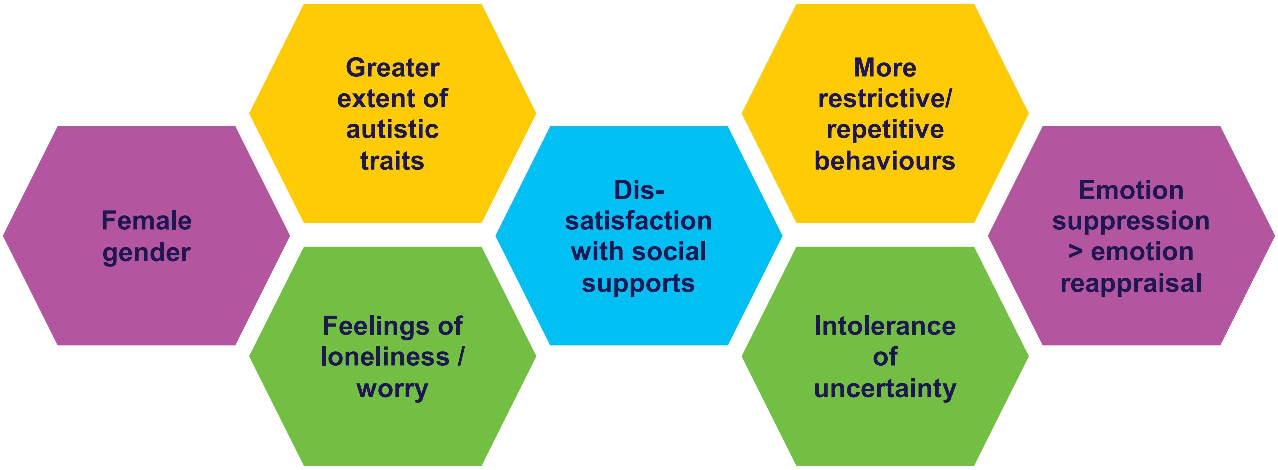
Table 12: Proportion of participants considered a ‘case’ on the HADS at each time point

Scale	Group	T1	T2	T3
Depression	**Autistic**	29%	23%	31%
	Autistic with ID	6%	9%	10%
	Non-autistic	26%	28%	34%
Anxiety	**Autistic**	64%	61%	55%
	Autistic with ID	66%	46%	32%
	Non-autistic	61%	52%	62%

4.2.2 Associated factors

Much of our research has been dedicated to identifying factors that place individuals on the autism spectrum at-risk of, or protects them from, experiencing mental health difficulties. The risk factors of interest examined at the time of writing included socio-demographic (e.g., gender), social (e.g., loneliness), cognitive (e.g., intolerance of uncertainty) and emotional characteristics (e.g., emotion regulation), and autistic presentation. A summary of these risk factors for SASLA participants can be seen in Figure 27.

Figure 27: Risk factors associated with factors related to mental and physical health



We found that female gender and a greater extent of autistic traits increased risk for anxiety and/or depression (Hedley et al., 2018; Uljarević et al., 2020). The risk conferred by autistic traits was due, in part, to feelings of loneliness and (dis)satisfaction with social supports (Hedley et al., 2018). Other factors which contributed to anxiety included feelings of worry, ‘intolerance of uncertainty’ (i.e., a tendency to negatively perceive and respond to uncertain events and situations), and increased restrictive and repetitive behaviours (Pem, 2015). Our research also suggests that restrictive and repetitive behaviours might predict anxiety through interplay with emotion regulation; specifically, autistic individuals with more restrictive and repetitive behaviours had increased difficulty regulating their emotions and, in turn, more symptoms of anxiety (Uljarević et al., 2017).[11]

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[11] Note that some publications referred to in this paragraph will include both SASLA and ALSAA data and others SASLA only data.

In addition to the factors described above, strategies used by autistic individuals to regulate their emotions were associated with risk for mental health difficulties. Autistic individuals who used 'emotion suppression' (avoiding uncomfortable emotions, e.g., by holding them in or thinking of other things) more often than 'cognitive reappraisal' (reframing a situation to change its emotional meaning, e.g., seeing a failure as a learning opportunity) had more anxiety and depression symptoms and lower positive well-being. Conversely, individuals who used reappraisal more often than suppression, or both strategies to an equally high amount, had better mental health outcomes.

Figure 28: Patterns of emotion regulation strategy use (cognitive reappraisal, expressive suppression) in relation to mental health symptoms.

Each of the four patterns is depicted in a separate column with speedometer icons used to depict high vs moderate vs low levels of each construct.

Our findings suggest that reappraisal may be a more adaptive emotion regulation strategy and protect against the negative effects of emotion suppression (Cai et al., 2018b; Cai et al., 2019; see Figure 28 for an illustration).

Investigation also revealed that the relationship between less adaptive emotion regulation (i.e., more suppression relative to reappraisal) and both anxiety and depression could be explained by degree of intolerance of uncertainty (Cai et al., 2018a).

Emotion regulation strategy use also predicted mood throughout the day. Autistic individuals reported lower in-the-moment mood than non-autistic peers and used more strategies for regulating negative emotions. Momentary mood was improved for individuals on the autism spectrum by savouring and accepting emotional experiences and reduced by dampening emotions and blaming others (Cai et al., 2020).

Behavioural inhibition (BI) is a pattern of temperament characterised by a tendency to experience negative emotions and withdraw from unfamiliar situations and/or people. Many individuals with high BI experience mental health problems. We investigated three aspects of self-regulation:

1. Attentional control (i.e., the ability to flexibly shift and focus attention),
2. Activation control (i.e., the ability to voluntarily engage a specific behaviour), and
3. Inhibitory control (i.e., the ability to voluntarily inhibit a specific behaviour).

We found that a history of high BI in childhood predicted anxiety problems for autistic youth with low levels of attentional or activation control. However, when autistic youth had high levels of attentional or activation control, high childhood BI did not predict anxiety problems. High childhood BI also predicted depression problems for autistic youth with low levels of activation control. Inhibitory control did not influence the relationship between childhood BI and mental health problems (Chetcuti et al., 2021 under review). These findings suggest that good self-regulation abilities may protect against mental health problems associated with BI in the autistic population.

Collectively, results from our research on mental health suggest that difficulties arise from multiple, interrelated risk factors many of which may be targeted by therapeutic supports.

4.2.3 Resilience/coping

Autistic adults experience high levels of stress, which may negatively affect their mental health. Research from the general population suggests that some coping strategies are more beneficial to mental health than others. This is the first study to explore how coping strategies influence the mental health outcomes of autistic adults. As a first step in answering this question, Melanie Muniandy (current SASLA PhD candidate) explored whether existing measures of coping fully capture the strategies used by the autistic community using SASLA and ALSAA data. Participants completed the Brief COPE questionnaire (Carver, 1997). While autistic and non-autistic adults (aged 15 to 77 years) used many of the same coping strategies, there were also some differences. Six coping styles, similar to those used by the non-autistic adults, best represented coping responses in autistic adults (Muniandy et al., 2021; Figure 29).

Figure 29: Six coping strategies for autistic youth and adults from the Brief COPE

1. Engagement

2. Support-seeking

3. Disengagement

4. Substance-use

5. Humour

6. Religious

4.2.3.2 Mental health outcomes

Melanie also explored whether coping strategies act as risk or protective factors for mental health outcomes in autistic and non-autistic adults aged 15 to 77 years of age (SASLA and ALSAA studies; Muniandy et al., under review). Melanie and the team found that:

- For autistic and non-autistic adults, the use of disengagement coping (e.g., strategies such as denial) was associated with increased anxiety and depression symptoms and reduced well-being.
- The use of engagement coping (e.g., strategies such as problem-solving) was associated with better well-being for autistic adults.

4.2.3.3 Resilience

Resilience describes the ability to maintain sense of wellbeing despite stress and/or adversity. Melanie explored relationships between resilience, coping and mental health in 72 autistic adults (Muniandy et al., 2021). Autistic adults who evaluated themselves as *less* resilient used more maladaptive coping strategies - i.e., those aimed at avoiding stress and/or associated distress, such as self-distraction and denial - which, in term, associated with higher anxiety and depression symptoms and lower wellbeing. Conversely, autistic adults who evaluated themselves as *more* resilient used more adaptive coping strategies - i.e., those aimed at resolving stress and/or associated distress, such as problem-solving and positive reappraisal - which, in turn, were associated with better wellbeing. Therefore, promoting resilience and the use of adaptive coping strategies may improve the mental health of autistic adults.

As Melanie's PhD progresses, it is emerging that the type of coping strategies an autistic person uses may act as either a protective or risk factor for anxiety, depression and well-being, and influence relationships between resilience and mental health outcomes. When addressing support options for mental health difficulties in the autistic adult population it is important to consider an individual's coping strategies and resilience.

4.2.3.3 Drug and alcohol use

When autistic SASLA participants with no ID were asked how they typically dealt with problems, we found that 6% were using alcohol or other drugs to make themselves feel better and 5% used alcohol or other drugs to help get through 'it'. The SASLA study also surveyed parents about the behaviours of their autistic children finding that 4% believed their child had "problems with cigarettes, alcohol or caffeine" and/or 2% had "problems with the illegal use of drugs".

4.2.4 Sleep

Poor sleep quality or insomnia can have a negative effect on multiple aspects of physical and mental health and can impair daytime functioning. It is very common for autistic people, with difficulty getting to sleep, night waking and shortened night sleep being most common sleep problems reported. Despite no-one in our sample reporting a diagnosed sleep disorder, based on their response on our sleep questionnaire[12], poor sleep quality was very common in all our SASLA participants (Table 13) and medication for sleep was taken at least weekly by 12.6% of autistic youth without an ID.

Table 13: Sleep quality of SASLA participants at all time points

	Autistic with ID			Autistic			Non-autistic		
	T1	T2	T3	T1	T2	T3	T1	T2	T3
Poor sleep quality	48%	42%	57%	57%	67%	58%	54%	51%	57%

In a preliminary study, we found that somatic complaints and sensory sensitivity are significantly related to sleep quality and that depressive symptom severity was associated with sleep quality (Miller, 2015) in young autistic adults aged 15-25 years.

Using SASLA and ALSAA data (Jovevska et al., 2020) we found that:

- Greater extent of autistic traits and the presence of a mental health condition, increased risk for poor sleep quality.
- Autistic females were at a higher risk for sleeping difficulties.
- Overall, poor sleep quality was more common for autistic individuals than non-autistic individuals across the lifespan (Figure 30).
- Autistic adults aged 20 to 59 years were at a highest risk for sleeping difficulties, while in adolescence sleep was poor for both autistic and non-autistic young people.

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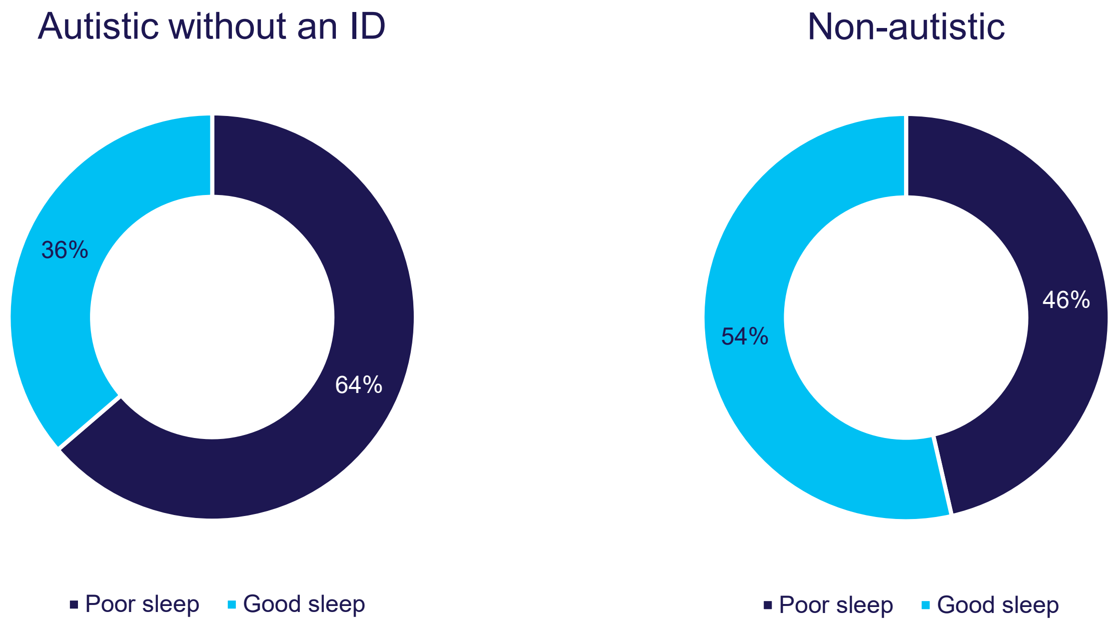
[12] Sleep quality was measured with the PSQI. Note that some information about sleep refers to SASLA and other information to the combined SASLA and ALSAA studies.

Figure 30: Rates of good and poor sleep in SASLA/ALSAA adults (15-80 years)



Alexa Chalmers, a SASLA masters student supervised by Professor Richdale and Dr Lawson, used statistical modelling to explore the nature of associations between sleep quality, anxiety and depression symptoms; and autism traits, sensory sensitivity, somatic (i.e., bodily) arousal, and Intolerance of Uncertainty (IU, i.e., flexibility) to these symptoms in the CALSA data (Chalmers, 2020). This preliminary analysis showed that:

- Somatic arousal, IU and sensory sensitivity were associated with anxiety.
- Somatic arousal, sensory sensitivity, and IU were associated with insomnia and depression through their relationship with anxiety.
- Somatic arousal was indirectly associated with depression through its relationship with sleep quality.

Targeting sensory sensitivity, behavioural flexibility and somatic arousal when addressing mental health and/or insomnia in autistic adolescents and adults may lead to improvements in sleep quality and anxiety and depression symptomatology.

Poor sleep and mental health are related to **fatigue** and daytime functioning. Our autistic participants without an ID also reported problems in keeping "*keep up enough enthusiasm to get things done*" in the past month (44%) indicating daytime disfunction. A third of autistic participants without an ID reported feeling distressed by fatigue 'moderately' to 'extremely'. Most recently SASLA investigated the impact of poor sleep quality, fatigue, and sense of contribution to community on depression symptoms at baseline. We found that both fatigue and lack of sense of contribution to one's community impacted depressive symptomatology in our autistic young people (Richdale et al., 2021).

We also explored sleep as one of several potential predictors of quality of life, as described in the following section.

4.2.5 Quality of life

We combined SASLA and ALSAA data to explore factors that contributed to autistic adults' quality of life (QoL) (Lawson et al., 2020). We found that autistic people experienced lower QoL on all four dimensions of QoL measured (detailed in Table 14) compared to non-autistic Australians. This table also shows the predictors of each QoL dimension. While mental health affects QoL in both autistic and non-autistic individuals with depression being a predictor for both Physical and Psychological QoL, depression was also a unique predictor of environmental QoL for autistic Australians. Additionally, a dependent living situation (e.g., living with parents) was related to poorer psychological QoL, while older age and being male were related to poorer social QoL for the autistic group.

QoL did not improve for autistic participants over a 2-year period, with psychological and social QoL staying the same and physical and environmental QoL declining. The best predictor for QoL for autistic Australians over two years was baseline QoL which was significantly lower than non-Autistic Australians to begin with. Examination of other predictors showed that psychological well-being, depression and sleep 2-years earlier continued to have an impact on psychological QoL 2-years later. Therefore, supports and strategies available to our autistic Australians from 2015 till September 2019 do not seem to have improved their QoL.

Table 14: Unique predictors of quality of life for autistic and non-autistic Australians

	Autistic Australians without an ID	Non-autistic Australians
1. Physical (E.g., Activities of daily life, dependence on medication, mobility, pain)	• Autism traits • Depression symptoms • Autonomic symptoms • Sleep quality	• Gender (male)[13] • Depression symptoms • Autonomic symptoms • Sleep quality
2. Psychological E.g., Negative and/or positive feelings, thinking, learning	• Living situation • Depression symptoms • Well-being	• Depression symptoms • Well-being
3. Social E.g., Personal relationships, social support, sexual activity	• Age • Gender (male) • Well-being	• Well-being
4. Environmental E.g., Financial resources, freedom, physical safety and security	• Depression symptoms	• Well-being

Opportunities exist for improving QoL for autistic Australians. The results of this study support the treatment of both mental health problems and sleep problems to assist in improving QoL and this may lead to improved psychological wellbeing for autistic adolescents and adults. For example, as sleep challenges (e.g., insomnia) are related to mental health, an intervention addressing both insomnia and mental health may be most useful in helping improve the QoL for autistic Australians.

4.2.6 Social connection

SASLA also asked about **social acceptance and supports;** only 33% of autistic youth with an ID reported feeling ‘satisfied’ or ‘very satisfied’ with support from their friends compared to autistic youth without an ID (62%) or non-autistic youth (58%). Approximately 30% of autistic youth without an ID reported that they did not seek emotional support from others. We also found that about a third of autistic young people with no ID felt disconnected from others:

- Rarely (or not at all) felt “*close to other people*” (28%).
- Often felt that “*people are around me but not with me*” (30%).
- Often or sometimes felt that there was no one to turn to (38%).
- Were twice as likely to have often felt “*isolated from others*” (30%) and “*left out*” (31%) than non-autistic youth.

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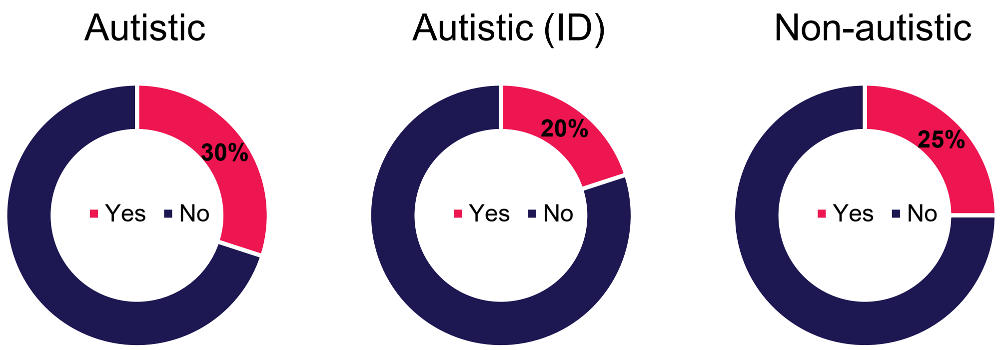
[13] Male and female only as the sample size was too small for analysis for other gender options.

- Were almost 3 times as likely to report a lack of companionship (28%) than non-autistic youth.

4.2.7 Suicidal ideation

One of our depression measures asked about suicidal ideation. Australian youth (15 - 25 years) reported high levels of suicidal ideation (20 - 30%) that is, thoughts or consideration of suicide at least several days per week in the preceding two weeks (Figure 31).

Figure 31: Percentage of participants who reported that they had suicidal thoughts (suicidal ideation) in the past two weeks.



Our findings reveal a concerning pattern of multiple and interrelated risk markers for suicidal thoughts and behaviours in the autistic population including:

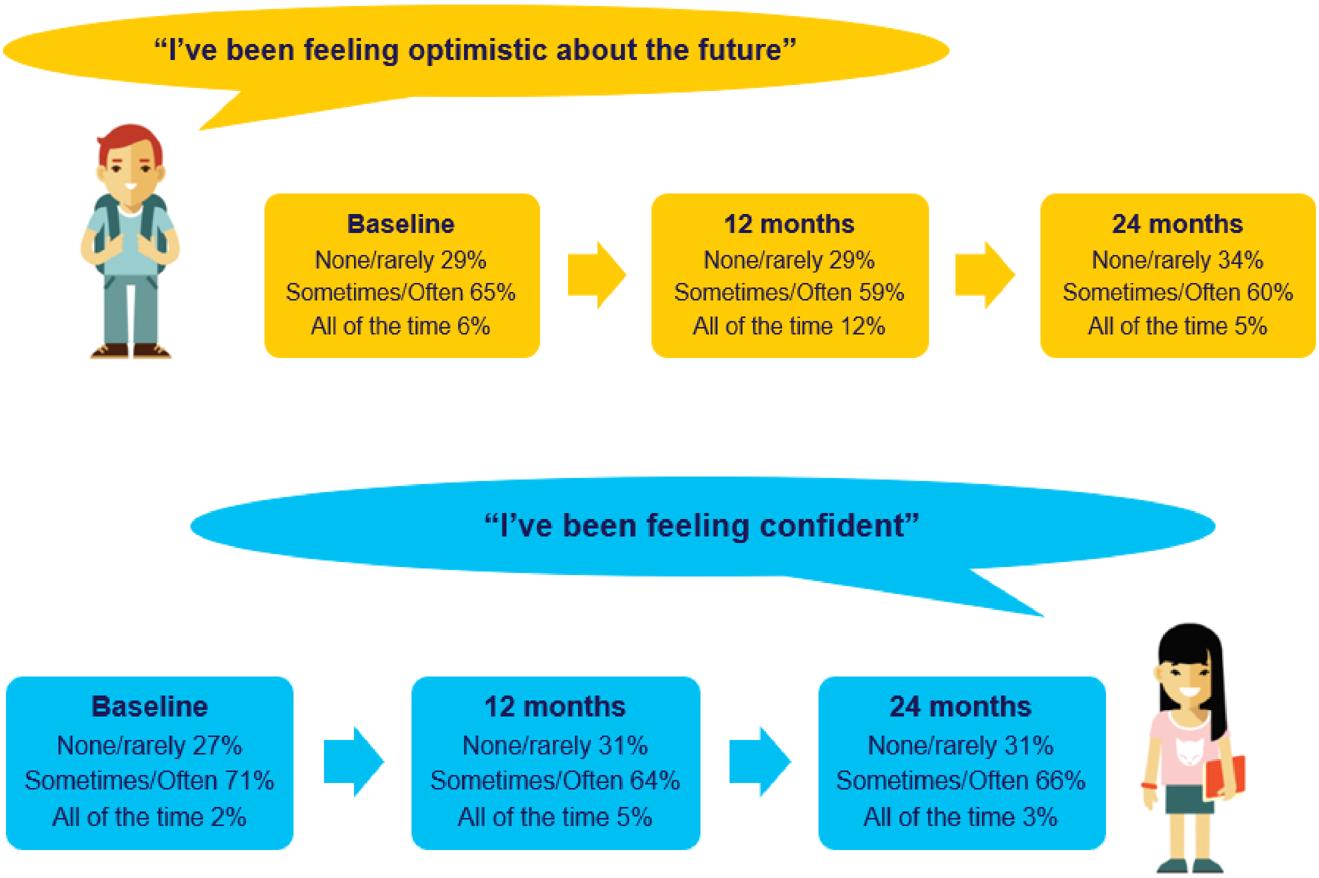
- High prevalence of co-occurring depression (see results in 4.2.1.2).
- High levels of loneliness (Hedley et al., 2018).
- Lack of satisfaction with social supports (Hedley et al., 2018).
- Feeling disconnected from others.
- High prevalence of poor sleep quality (Jovevska et al., 2020).
- 19.7% of autistic adults had experienced suicidal ideation in the last 2 weeks (2.4% in general population) this increased to 36% if individuals reported clinical levels of depression symptoms (Hedley et al., 2018).
- Lower reported loneliness and higher satisfaction with social supports was protective against depression and suicidal ideation (Hedley et al., 2018).

When considering the mental health of autistic adults, satisfaction with social supports is more important than the quantity of social supports and thus reducing loneliness could buffer against suicidal ideation. It is very likely that these factors have a significant impact on the quality of life experienced by autistic Australians.[14]

4.2.8 Preliminary longitudinal exploration of well-being

Participants also answered questions about their wellbeing. At each time point approximately 30% of respondents were not feeling optimistic about the future, and approximately 30% were not feeling confident. Figure 32 shows the proportion of autistic participants with no ID feeling optimistic and/or confident about their futures.

Figure 32: Young autistic (without an ID) Australian's optimism and confidence in the future over time



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[14] These finding include SASLA and ALSAA data

4.3 The health and wellbeing of parents/carers

SASLA also surveyed parents/carers of autistic young people. We asked parents/carers of autistic individuals about their experience during this time, as we wanted to understand this period from their point of view in addition to that of young people.

4.3.1 Challenges experienced by parents/carers

Because of either the absence or the inadequacy of services the burden of supporting autistic children, adolescents, and adults in Australia usually falls on their parents and the impact on families in terms of social, emotional and economic stress can be extensive (Flower et al., 2019). Dr Nancy Sadka (OTARC researcher, and parent of an autistic adolescent and an autistic young adult) gave a first-person account of what is required from a parent of autistic children/adults describing:

- Difficultly navigating the NDIS.
- The large amount of preparation needed to ensure adequate funding every year, including making sure to account for the “8,760” hours per year spent on caring duties.
- Need to keep up to date with a constantly changing system.
- Implementing an NDIS plan is a full-time job – where navigating lack of knowledge of autism, rostering staff, lodging timesheets, invoicing providers, bookkeeping and budgeting are just the beginning.

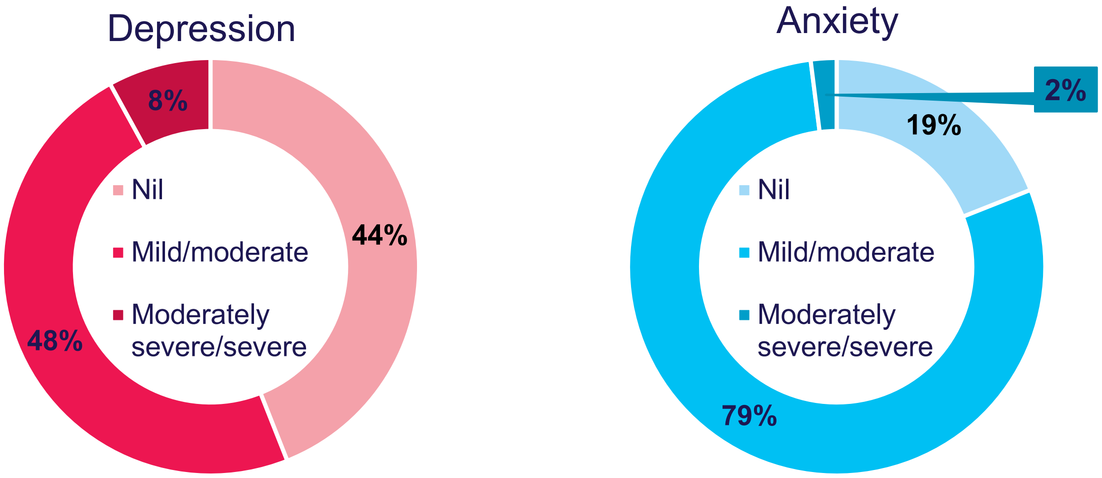
The failure to provide adequate services that are easy to navigate, and access comes with a significant cost in terms of time, stress and dealing with uncertainty not only to autistic people but also for those who support and care for them (Flower et al., 2019).

4.3.2 Mental and physical health challenges

SASLA also asked parents/carers about their mental health and found that most were experiencing mild to severe depressive and/or anxiety symptoms at the time of the baseline survey (Figure 33). Sleep issues were also commonly reported with 54% of respondents having trouble sleeping at baseline.

> ***Most of my anxiety stems from fear for my autistic daughter’s future (Parent of autistic young person).***

Figure 33: Clinical levels of anxiety and depression symptoms experienced by parents/carers of autistic Australians.



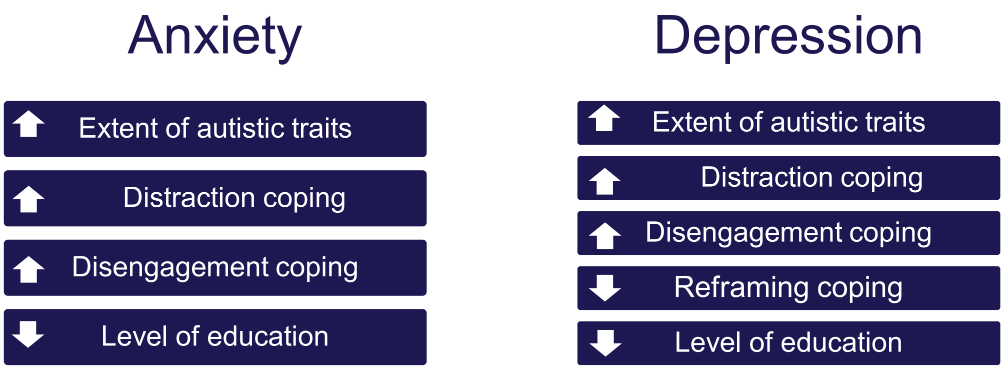
The high levels of sleep difficulties, anxiety and depression in this sample suggest that there is an urgent need for mental health support for parents/carers of autistic people. Supporting carers can only improve the wellbeing and quality of life of their dependents and in turn benefit the wider community.

4.3.3 Cross-sectional coping and emotional distress

Even though parents/carers of autistic young adults experience higher rates of anxiety and depression than the general population, little is known about the influence of coping on their emotional distress. Master's student, Carol Bryden, studied relationships among caregivers' coping responses, emotional distress (symptoms of anxiety and depression), and selected background variables (caregiver and young adult autistic traits, caregiver strain), examining their associations for parents/carers of autistic transition aged youth at baseline (Bryden, 2020; Figure 34).

These findings indicate that for caregivers of autistic young adults, behavioural coping strategies aimed at detaching oneself from a stressor (e.g., denial) may exacerbate emotional distress, while strategies aimed at changing the way one thinks about or relates to a stressor (i.e., positive reframing) may help to reduce symptoms of depression.

Figure 34: Predictors of anxiety and depression for parent/carer of autistic young adults



These findings suggest that supports aimed at reducing emotional distress for parents/carers should focus on promoting the use of cognitive strategies such as positive reframing in place of ineffective coping strategies such as distraction and disengagement. Such supports have potential to improve the wellbeing not only of the parent/carer but also the whole family unit.

4.4 Psychometric validation and scale development

4.4.1 Validated scales for measuring anxiety and depression in autistic adults.

Using SASLA and/or ALSAA data we explored the validity and reliability of two questionnaires that measure anxiety and depression in autistic populations.

The Hospital Anxiety and Depression scale (HADS; Zigmond et al.,1983)

The HADS scale measures anxiety and depression symptoms in the past week. Using a sample of 45 SASLA (Australian sample) + 151 UK Transition longitudinal study (UK sample) autistic adolescents and young adults we found that:

- The HADS demonstrated statistically similar properties in the autistic sample to a non-autistic sample, with good Internal consistency (Cronbach's alpha) α = .83 and good convergent and divergent validity (Uljarević et al., 2018).

The HADS can be used by clinicians to measure anxiety and depression in autistic adolescents and young adults aged 14-25 years

Patient Health Questionaire-9 (PHQ-9; Kroenke et al., 2001)

The PHQ-9 measures depression symptom severity and functional impairment in the last 2 weeks. The scale also has a single item measuring suicidal ideation using an Australian sample of 346 autistic + 235 community comparison participants from the SASLA and ALSAA studies ages 15-80 years we found that:

- The PHQ-9 demonstrated statistically similar properties in the autistic sample to the non-autistic sample. There was excellent internal consistency (Cronbach's alpha) for autistic and community comparison samples $\alpha = .91$ and the PHQ-9 demonstrated good convergent validity (Arnold et al., 2020a).

The PHQ-9 can be used by clinicians to measure depression in autistic youth and adults aged 15-80 years.

4.4.2 Development of an Impact of Diagnosis Scale-Preliminary Revision

(Arnold et al., 2020b)

The ALSAA (lead) and SASLA teams developed a revision of the Impact of Diagnosis Scale (IODS; Courtney et al.,2016) for use with autistic adolescents and adults. The ALSAA team worked with autistic research advisors to create the IODS–Preliminary Revision (IODS-PR), which has 12 items scored on a 7-point agree/disagree scale and two open-ended questions. An autistic advisor helped to interpret the results. There are three subscales:

1. Self-Acceptance and Understanding.
2. Being Understood.
3. Service Access.

Thematic analysis[15] of 160 responses identified 5 themes (Figure 35). The impact was reported as positive or negative depending on the individual person.

Figure 35: The five themes from the Impact of Diagnosis Scale open ended questions

1. Self-Understanding, Identity, and Acceptance

2. Supports and Services (Enabled Support, Support not needed, and No or poor services)

3. Valence of Response (Relief, Positive impact, Wish diagnosed earlier, and Negative impact)

4. Relationships (Connected with autistic community, Improves relationships, and Others lack understanding)

5. Camouflaging

The refined IODS for autism can be used to evaluate support services and help clinicians understand how to create a more positive experience and response to an autism diagnosis. More research is needed to understand how to support the diagnostic process for adults.

---

[15] Thematic analysis helps us identify themes in open ended responses.

4.4.3 Evaluation of an Australian version of the Vocational Index for Adults with Autism (Sahin et al., 2020)

The Vocational Index for Adults with Autism (VIAA) is an assessment of vocational independence. A representative Australian sample (autistic *n* = 105, non-autistic *n* = 106 aged 17 to 26 years of age; including SASLA participants) was used to examine the psychometric properties of a modified version of the VIAA (M-VIAA) for the Australian context. Vocational independence was higher in non-autistic participants than in autistic participants. Vocational independence was not related to daily living skills, however, it was related to autistic traits. Over 2 years, scores on the M-VIAA changed little for the autistic participants. While the results provide some initial support for the M-VIAA, we also identified that the instrument may not represent the full range of challenges, nor the richness of vocational activities experienced by autistic individuals in post-secondary vocational settings.

4.4.4 Factor structure and psychometric properties of the Brief COPE (Carver, 1997) in autistic older adolescents and adults

The Brief COPE assesses dispositional coping (general coping style). A representative Australian sample (*n* = 255 aged 15 to 80 years of age [SASLA + ALSAA data]) were used to validate and investigate the psychometric properties of the scale in this autistic population. See Section 4.2.3 for further information). The Brief COPE had high reliability and good convergent and divergent validity for each of the conceptually relevant coping factors that were found (Muniandy et al., 2021).

4.5 COVID-19

In April 2020, SASLA introduced a series of questions about the impact of COVID-19 on young Australian adults (Appendix 4). Sixteen participants responded the COVID-19 general questions and nine responded with extended qualitative responses[16]. The most frequently used words for autistic participants were sleep, anxiety and worse (Figure 36) compared to our non-autistic participants who used work, stress, and anxiety to describe their COVID 19 experiences.

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[16] Our final 65 (autistic *n* = 22/20%, non-autistic *n* = 43/66%) participants to complete the final survey

Autistic participants were twice as likely to describe the pandemic as having a very negative impact on their lives (Figure 37). A thematic analysis of written responses (Autistic *n* = 4 [19 individual item responses], non-autistic *n* = 5 [17 individual item responses]) can be found in Table 15. Three themes were identified from the autistic responses (change, sleep, and stress). The cumulative life stress may on impact suicide risk and development of mental health problems.

Figure 36: Frequency of sentiment expressed by young adults when describing the impact of COVID 19

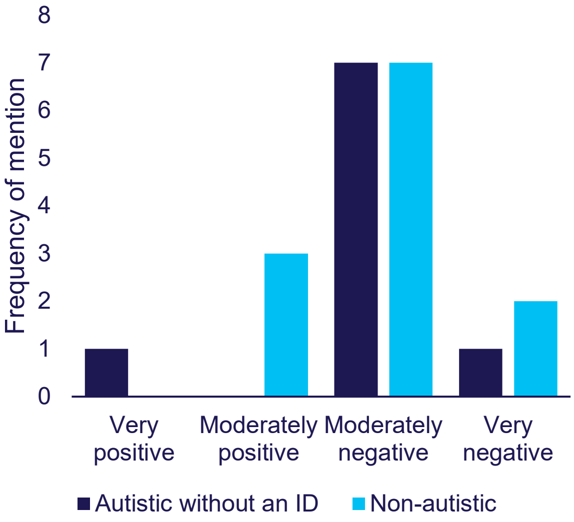


Figure 37: Frequency of words used by autistic youth without an ID to describe the impact of COVID 19 on their lives

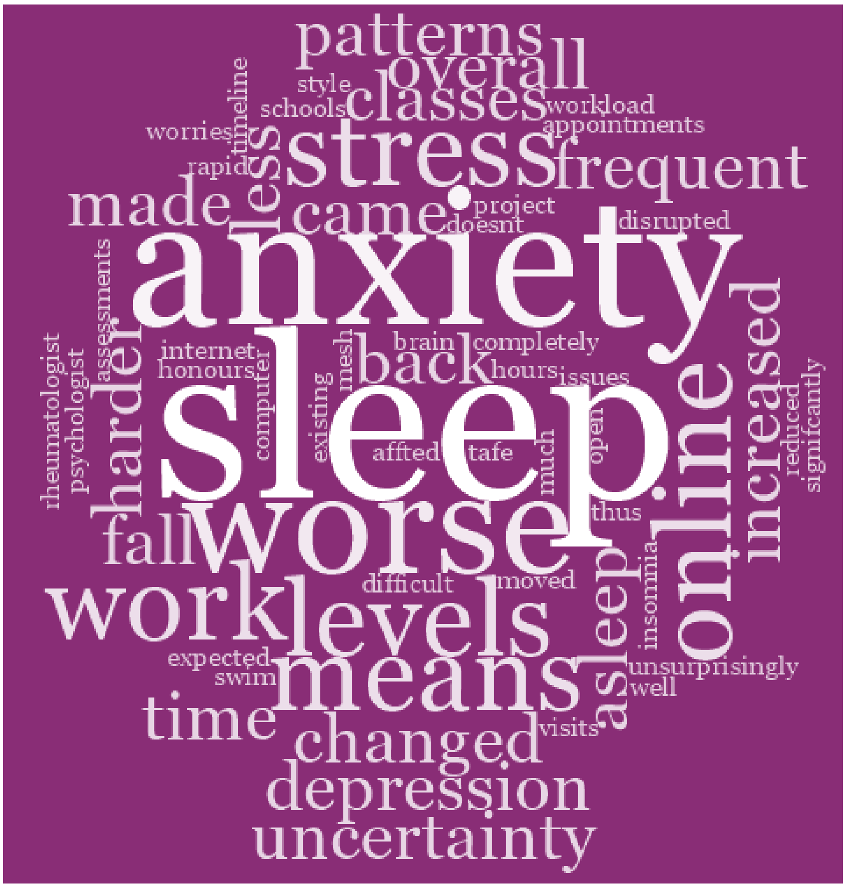


Table 15: Themes identified from text responses to the COVID 19 survey

Autistic without an ID		Non-autistic	
1. Change	*"Depression came back, unsurprisingly rapid changes and uncertainty did not mesh well with my brain"* *"Reduced hours, affted honours project timeline signifcantly, changed style of workload and assessments"*	**1. Online**	*"Everything was closed and moved online. My hours at work changed so I couldn't go to the online youth groups even when they didn't change thir hours."* *"TAFE moved online which has impacted my willingness to study and attend sessions."*
2. Sleep	*"Anxiety worsening sleep patterns."* *"Sleep: Stress levels have made it harder to fall asleep on time, means I get less overall sleep"*	**2. Work**	*"I quit my job when it began due to stress and anxiety and have a new job but I have reduced hours"* *"Working in retail resulted in increased stress from anxious customers. Work shifts are longer increasing stress."*
3. Stress	*"Stress levels have increased significantly more than expected."*		

4.6 Other

4.6.1 Sex and age differences in Restricted and Repetitive Behaviours and Sensory Signs and Symptoms

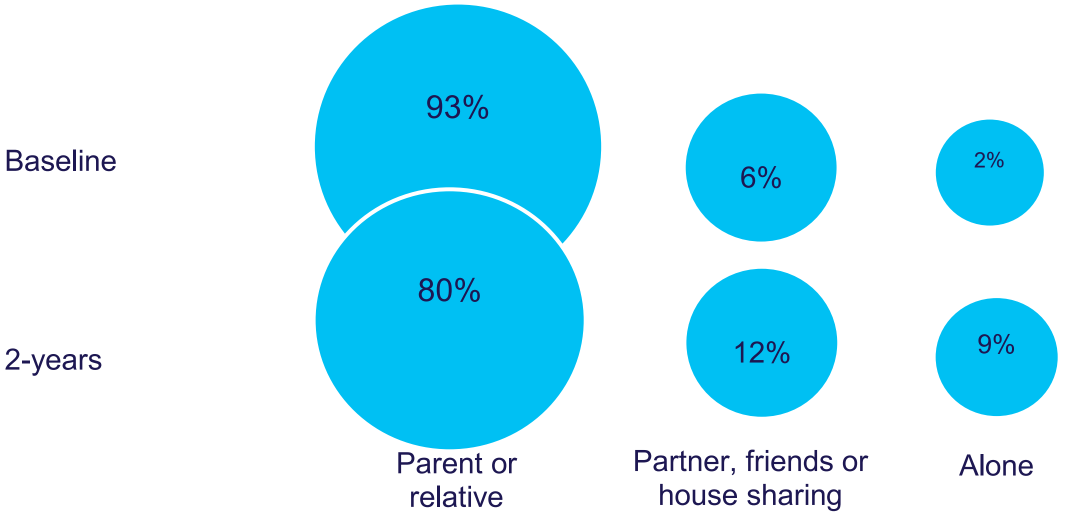
We investigated gender (male/female) and age differences in self-reported restricted and repetitive behaviours (RRB) and sensory signs and symptoms (SSS) in autistic and non-autistic Australians (15-79 years) to determine if age or gender were related to RRB or SSS severity. We found that autistic people experienced more RRBs including insistence on sameness and repetitive sensory motor behaviours, and SSS than non-autistic people (Lewis, 2020). Both autistic and non-autistic older participants (60+ years) reported fewer RRBs than people aged 15–59 years (Lewis, 2020). We found that:

- Autistic and non-autistic female participants reported experiencing more SSS than males.
- Autistic females reported experiencing more RRB's and SSS than autistic males.

4.6.2 Preliminary exploration of living situation from baseline to 2-years

Autistic young adults with no ID and non-autistic young adults were significantly less likely to be living with parents/relatives and more likely to be living independently (with partners, friends, share housing or alone) by 2-year follow up (Figure 38).

Figure 38: The living situation of autistic young adults without an ID from baseline to 2-years



5. Utilisation

In line with the Autism CRC's vision "to see autistic people empowered to use their diverse strengths and interests" and mission "to motivate, facilitate and translate collaborative autism research, across the life-span and the spectrum, underpinned by inclusive practices" the SASLA team has strived to make practical and effective use of the data that our participants generously provided to:

- Disseminate the findings of our research to the autistic community (individuals, families, organisations, professionals) and the international research community through peer-reviewed publications, presentations, media coverage, newsletters, and the production of end-user identified resources.
- Contributing to Federal and State policy through Select and Senate enquiries and consultation on areas of expertise).
- Nurturing researchers - early career (postdoctoral) and new (PhD, Masters, Honours, and undergraduate placement students).

5.1 Dissemination

The SASLA team has used a variety of active pathways to disseminate its research findings and activities. The SASLA team has been prolific in its dissemination of results and materials to its participants, community members and to the broader scientific community including 16 peer-reviewed publications using SASLA data (a further 4 are currently under review), 55 conference presentations, 30 media outputs, and 14 resources for end-users. Additionally, SASLA team members, including our PhD and Masters students, have published a further 29 peer-reviewed papers (Appendix 5) related to autistic children, adults or carers of autistic young people.

5.1.1 Peer reviewed publications

Our publications have included many of the themes identified by our autism community partners in the 2014 Adult Forum including vocation (e.g., employment), emotional regulation, mental and physical health, and parents and later reiterated in our 2020 survey of the SASLA community (see Figure 39). A full list of papers is provided in Appendix 5.

Figure 39: Overview of SASLA peer-reviewed papers by category

16 **Total SASLA publications**	5 Psychometric properties	4 Emotion regulation and temperament (+1 under review)	5 Mental and physical health (+1 under review)
1 Vocation	2 Coping/ resiliance (+1 under review)	1 Parent	The autistic experience (+1 under review)

In terms of **academic impact** (SciVal 2016 – 2021), publications containing SASLA data have a field weighted citation impact (FWCI) of 3.85 which is over 3.8 times the world average. Our most cited publication is '*Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder'* (44 citations and a FWCI of 6.30). Almost 65% of SASLA articles were in the top 10% of most cited publications worldwide, 55% have an international co-author, and 27% are published in open access journals.

5.1.2 Conference presentations

The findings from SASLA research have also been widely disseminated within the research community through the SASLA team presenting at more than 50 times at national and international conferences (presentations and posters). A full list of conference presentations is provided in Appendix 6 and Figure 40 details the numbers by presentation audience.

Figure 40: SASLA conference presentation numbers by audience

Presentations	6 Conference - keynote or invited	16 Conference (oral or poster)	16 Invited/community talks
4 Online sway presentations	4 Webinars	2 CRC board presentations	5 Professional development talks

5.1.3 Media, community presentations and communication

In addition to these traditional avenues of research dissemination (i.e., peer-reviewed articles and research conferences), the SASLA team has tried to be creative in making our findings as accessible as possible to the wider community. A full list of non-traditional outputs can be found in Appendix 7. Our methods of communication include:

- 3 blogs
- 3 webinars
- 4 videos
- 2 periodical articles
- 18 newsletters

The team has also accepted many invitations to speak on a variety of topics to community groups, universities, autism specific service providers, and professional development for professional groups.

At the beginning of the study the team produced an annual newsletter and communicated with stakeholders and participants via email during the year. Since September 2017, we have produced a quarterly newsletter which is disseminated to participants and stakeholders to update on team activities, project progress, and to increase community engagement. Newsletters included the introduction of new team members, putting friendly faces at the forefront of our research. We also included simple descriptions of our most recent publications and offered opportunities for participation in other Autism CRC projects and partner events.

The quarterly newsletters have been well received by participants and organisations averaging a 45.4% open rate, with every issue exceeding the not-for-profit benchmark of a 19.1% open rate. Table 16 shows the open rates for each issue since September 2017.

Table 16: SASLA newsletter open rates from September 2017 – June 2021

** Not split for distribution. [a] no metrics available.*

	Individuals	Organisations	
September 2017	43.3%	47.2%	**Benchmark (not-for-profit) 19.1%**
December 2017	45.0%	26.8%	
March 2018	26.8%	27.3%	
July 2018	53.9%	43.6%	
October 2018	33.4%	38.2%	
December 2018	44.1%*		
March 2019	49.9%*		
July 2019	48.6%*		
October 2019	36.3%*		
December 2019	26.0%	32.2%	
March 2020	48.8%	33.3%	
June 2020	30.9%	29.0%	
September 2020	30.7%	30.2%	
December 2020	31.4%	44.4%	
March 2021	25.7%	38.5%	
June 2021	[a]	[a]	

The SASLA team actively promotes community engagement by attending community stakeholder events, for example Northland's sensory shopping day, Awetism 2017 and 2020 (I CAN Network), Different Journeys teen and adult Social Dinners, Ticket to Work 1000 job placements for young people with a disability celebration, and many more. We reported our experiences at these events in our newsletter.

5.1.4 End-user resources

All resources listed are available on the Autism CRC website and are listed below (Figure 41).

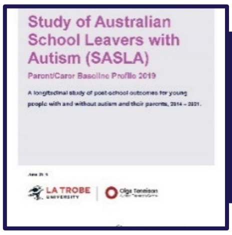
Figure 41: SASLA end user resources

Study of Australian School Leavers with Autism (SASLA)

Baseline Profile 2018

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

Baseline Profile 2018



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.

Parent/Carer Baseline Profile 2019

Study of Australian School Leavers with Autism (SASLA)

Longitudinal Profile 2019

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

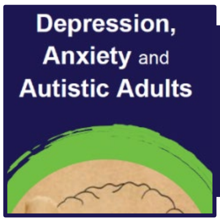
Longitudinal Profile 2019

SLEEP AND YOUNG AUTISTIC ADULTS

Sleep and young autistic adults

Supporting mental health: What young Australian autistic adults tell us

Supporting mental health: What young Australian autistic adults tell us



Depression, Anxiety and Autistic Adults

Depression, anxiety and autistic adults

5.2 Contributions to policy

5.2.1 Royal Commission into Victoria's Mental Health System - 2019

Access the submission here

The SASLA team compiled data from young autistic adults (15 to 25 years of age) in Victoria to give a snapshot of the prevalence of mental health difficulties experienced by autistic youth and how this may be contributing to their employment and study participation.

5.2.2 Select Committee on Autism – 2020

Access the submission here

The Select Committee on Autism was announced in November of 2019 to inquire into and report on the services, support, and life outcomes for autistic people. The Terms of Reference for the Select Committee were very broad offering SASLA the opportunity to contribute to an OTARC (La Trobe University) submission. Feedback from our SASLA community was vital to ensure the focus of our contribution to the La Trobe University submission for consideration by the Select Committee on Autism. We undertook a SALA community survey to autistic individuals, families, community groups and researchers via our newsletter mailing list. Twenty-two community members responded, and selected quotes were published to give context to the SASLA survey data.

> ***“An autistic person that is well adjusted can work, often in highly skilled work and contributes significantly to the Australian community (even if it takes more effort up front), whereas one who is not, becomes a burden financially and socially to those around them.” (Autistic individual)***

The submission made 25 recommendations to the Committee and is available on the Committee’s website and through La Trobe’s open access repository, OPAL (578 views, 132 downloads). The submission also led to the creation of 5 online presentations that included SASLA work (150 average views per presentation):

1. SASLA's contribution to the Australian Select Committee on Autism.
2. Current approaches and barriers to consistent, timely and best practice autism diagnosis.
3. Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services.
4. The demand for and adequacy of Commonwealth, state and local government mental health services.

5. The demand for and adequacy of Commonwealth, state and local government transition-to-study services.

The submission also resulted in invitation to attend a public hearing on the 12th February 2021. Professor Richdale presented on behalf of OTARC and the Autism CRC (SASLA). The Select Committee also toured the OTARC research facilities in April 2021. You can find a full transcript of the hearing here[17].

5.2.3 Education and Employment Legislation Committee: Comment on the Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020

Access the submission here

When the Education and Employment Legislation Committee opened for submission to comment on the proposed changes to higher education funding OTARC composed a response detailing the ways the Bill would disadvantage the autistic community and the SASLA team provided a substantial contribution to the final submission. A copy of this submission is in the OPAL repository (435 views, 129 downloads).

> ***Final recommendation:*** Given that there is no provision within this Bill to expand funding for existing support services either to autistic higher education students, or to autistic high school students transitioning to further study, Schedule 4, Part 2, 36 13 of the Bill is likely to unfairly disadvantage autistic Australians and should be deleted.

Outcome: Due to submissions from advocacy groups the bill was amended to make special consideration more readily available to vulnerable students.

5.2.4 Access to TAFE for learners with a disability Victoria, Australia - 2020

Access the submission here

The SASLA team commented on: (1) social and economic benefits of increasing accessibility to Victorian TAFE, (2) experiences of learners accessing and participating in TAFE programs, (3) barriers to learning, and (4) what teachers and staff require to maximise learning experience. A copy of this submission is available in the OPAL repository (540 views, 152 downloads). Asperger's Victoria directly referred to our work in their submission to the enquiry.

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[17] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Public_Hearings

5.2.5 Productivity Commission Report on Mental Health - 2021

The SASLA team provided consultation on the report. We commented on recommendations 4, 6, 9,10, and 16 to increase the Productivity Commission's understanding of the unique needs of young autistic adults with co-occurring mental health difficulties in Australia.

5.2.6 Select Committee on Mental Health and Suicide Prevention - 2021

Access the submission here

Professor Richdale led a substantial La Trobe University submission (No. 89) to the Committee. A copy of this submission will be available in the OPAL repository. The SASLA team and OTARC felt very strongly about bringing our research to the attention of policy makers in this space. This submission contained 20 recommendations regarding mental health and suicide prevention for autistic people broadly covering:

- Informed service provision for autistic people.
- Accommodations and adjustments to usual practice for autistic people.
- Specialist service availability, development, and expansion.
- Education and training of service providers.
- Research.

The submission has resulted in invitation to attend a public hearing on the 26th of July 2021.

5.2.7 Draft National Preventive Health Strategy 2021-2030 consultation

Given the high rate of sleep difficulties in autistic people, SASLA wrote a letter to the National Preventive Health Taskforce expressing our concern and disappointment that sleep was not considered as a fundamental area of interest in the Draft National Preventive Health Strategy 2021-2030. The lack of inclusion of sleep as a target for the prevention of health difficulties in Australia was a critical oversite in the report.

> ***Final recommendation:*** Acknowledge the significant impact of sleep on the health and well-being of Australians through the inclusion of an additional key focus area – Improving sleep health.

5.3 Nurturing up-and-coming researchers

5.3.1 Postdoctoral researchers

Dr Mirko Uljarević (2014 -2017). Mirko investigated repetitive behaviours and how these behaviours are related to sensory problems and anxiety in autistic children and adolescents for his PhD at the Cardiff University (UK) finishing in 2014. Mirko received the College of Science, Health & Engineering Fellowship for Early Career Researchers Award (AUD $3800) and is currently an ARC Senior Research Fellow (DECRA) with the University of Melbourne School of Psychological Sciences.

Dr Lauren Lawson (2017-2021). Lauren completed her PhD at the University of Western Australia in 2015. Lauren is a clinical psychology registrar and is passionate about using large datasets to identify areas of strength and difficulty for autistic individuals and using these data to inform development of supports. Lauren won the La Trobe University Research Rumble Judges Choice and People Choice awards. See her 5-minute talk about an Insomnia Intervention for Autistic Adults https://www.youtube.com/watch?v=wNQAvVa-Ge8. Lauren is currently on maternity leave.

> ***"It has been so rewarding to be involved with a project that has clear and practical outcomes for autistic adults. In particular, it has been amazing to see the data that you all so generously provided be used in several submissions to the state and federal government to lobby for policy changes. I am hopeful that these submissions will lead to positive changes for the autism community."***

Dr Rebecca Flower (2018 - 2019). Bec completed her PhD at Flinders University looking at autism and the criminal justice system and graduated in early 2017. Bec has a passion for positive outcomes for autistic adults and looks forward to analysing the SASLA data to see what is happening for transition-age youth on the spectrum in Australia. Bec is now a lecturer in psychology for La Trobe University on the regional Bendigo campus.

> ***"I very much enjoyed my time working on the SASLA project and am grateful for the opportunity to learn from the experiences of young autistic adults. Your generous input allowed us to see what was happening for young autistic people and speak about challenges in places where people might be able to make positive change. Thank you for your time."***

Dr Susan M. Hayward (2020). Susan completed her undergraduate degrees (BSc (Psych.), Grad Dip. Psych.) at Deakin University, and her PhD at The University of Melbourne, finishing in 2018. Susan's research interests include employment and social inclusion of individuals on the autism spectrum, and psychological health and well-being. Susan is now a lecturer in Disability and Inclusion at Deakin University.

> ***"I've learned so much from being a part of this team in this very challenging year, so thank you all."***

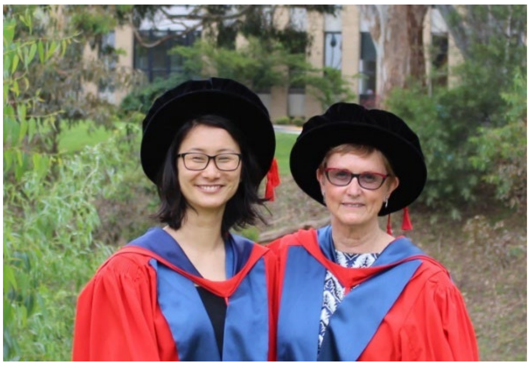
Dr Ifrah Abdullahi (2020). Ifrah holds a PhD from the School of Paediatrics and Child Health, the University of Western Australia. Ifrah is a passionate and talented science communicator and a strong advocate for children of immigrant, minority and refugee backgrounds in Australia. Ifrah is currently on maternity leave.

> ***"It's been an absolute pleasure to work on the SASLA project in such a challenging year. I have enjoyed learning from autistic young people and adults, as well as working with my colleagues at SALSA. Thank you for this wonderful opportunity and farewell." (Dec 2020)***

Dr Lacey Chetcuti (2021). Lacey completed her PhD at La Trobe University in early 2021 studying the ways in which young children with autism are inherently different from each other with regard to temperament, and how this relates to later autism and developmental outcomes. Lacey plans to continue working in autism research and will move to a new position in Psychology and Counselling at La Trobe.

> ***"I have thoroughly enjoyed my short but sweet 6-months on the SASLA study. I have learned an incredible amount from this dedicated community of participants and researchers that I will take with me into my future career, wherever that may be. Thank you all for giving me this opportunity." (June 2021)***

5.3.2 PhD



Ru Yin Cai (graduated 2018; photo to the right) "*Emotion regulation and psychological wellbeing in young and older adults with autism spectrum disorder*". Ru was awarded the International Society for Autism (INSAR) Research meeting travel award. Ru published 6 journal articles associated with her PhD research:

1. Brief report: Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms in autism spectrum disorder, https://doi.org/10.1016/j.rasd.2017.10.002
2. Emotion regulation in autism: Reappraisal and suppression interactions, https://doi.org/10.1177/1362361318774558
3. How does emotion regulation strategy use and psychological wellbeing predict mood in adults with and without autism spectrum disorder? A naturalistic assessment, https://doi.org/10.1007/s10803-019-03934-0
4. Emotion regulation in autism spectrum disorder: Where we are and where we need to go. https://doi.org/10.1002/aur.1968

5. Resting heart rate variability, emotion regulation, psychological wellbeing and autism symptomatology in adults with and without autism, https://doi.org/10.1016/j.ijpsycho.2018.12.010

6. Brief Report: Inter-relationship between emotion regulation, intolerance of uncertainty, anxiety and depression in youth with autism spectrum disorder, https://doi.org/10.1007/s10803-017-3318-7

Ru is currently a postdoctoral researcher at Aspect, a research supervisor at Monash University and sits on the Different Journeys Board.

Melanie Muniandy (in progress). "*Social Support, coping, and resilience in autistic adolescents and young adults*". Melanie is currently on maternity leave and hopes to complete her PhD early in 2022. She has published two journal articles to date associated with her PhD research:

- Factor Structure and Psychometric Properties of the Brief COPE in Autistic Adults, https://doi.org/10.1016/j.rasd.2021.101764

- Inter-relationships between trait resilience, coping strategies and mental health outcomes in autistic adults https://doi.org/10.1002/aur.2564

5.3.3 Masters of Psychology (Clinical)

Andrew Halim (2016-2017) Explored the presentation and experience of anxiety in autistic older adolescents and young adults. This resulted in the publication:

- Exploring the nature of anxiety in young adults on the autism spectrum: A qualitative study, https://doi.org/10.1016/j.rasd.2018.07.006

Alexa Chalmers (2018-2019) Examined transdiagnostic predictors of anxiety, depression and sleep quality in the SASLA/ALSAA data set using path analysis. A manuscript from Alexa's work is in preparation. A summary of her findings has been reported within conference/seminar presentations on sleep and mental health.

Carol Bryden (2020). Worked with the SASLA team and collaborator Dr Eric Morris (La Trobe Psychology Clinic Director and academic) to explore coping and emotional distress in family caregivers of autistic young adults. Carol passed her course in 2020. A manuscript from Carol's work is in preparation.

Louise Dickens (2020-current) Working with the SASLA team and Dr Eric Morris (Director, La Trobe University Psychology Clinic) investigating the relationships between depression, fatigue and sleep difficulties in autistic adolescents and adults. Louise is currently cleaning her data in preparation for analysis.

5.3.4 Honours

Samantha Lewis (2020). Repetitive behaviours and their stability over time. See findings in Section 4.6.1. Samantha is currently preparing a manuscript for publication.

Sanya Jovevska (2019). Sleep patterns and problems in adolescents and adults with high-functioning autism spectrum disorder: Examining gender and age-related differences. This resulted in a peer-reviewed paper:

- Sleep Quality in Autism from Adolescence to Old Age, https://doi.org/10.1089/aut.2019.0034

Ensu Sahin (2019). Examined the relationship between depression, anxiety, sleep problems and daytime fatigue have with independence in Australian autistic youth see 4.1.1.2.

Kate Miller (2015). Factors Affecting Sleep in School Leavers with Autism Spectrum Disorder. See findings in Section 4.2.4.

Anshula Devi Pem (2015) An Investigation of Anxiety in School Leavers with Autism Spectrum Disorder Compared with Typically Developing School Leavers. See findings in Section 4.2.2.

5.3.5 Undergraduate placement students

Josh Vartuli (2019). Josh is a La Trobe University student who completed a placement subject with the SASLA team. Josh helped us with a peer-reviewed journal submission and became a co-author on this article (Lawson et al., 2020). Josh is autistic and has offered valuable insights and perspectives to the team. Alex (SASLA Research Officer) sat with Josh for a quick interview about his experiences working with the SASLA research team. This was published in the SASLA and OTARC newsletters and on the OTARC blog. You can read the whole interview here[18].

> ***Q: What is it like experiencing research for the first time from the researcher perspective?***
>
> ***"I've been part of the research as a participant but being in the background, working out how to, so stuff is really interesting. What systems you use, seeing the data sets before you see the results. That's the hardest thing is working with the data sets to work out what's good and…what can't be used. It's a brand-new experience and an experience I like."***

Lisa Wong (2020). Lisa undertook a placement at OTARC working with the SASLA team to broaden our understanding of how we may be able to reduce the effect of the flight or fight response (i.e., arousal) on anxiety, worry and sleep in autistic young adults. Lisa hopes to continue her studies and pursue a Master's in Clinical Psychology. This work resulted in a peer reviewed oral presentation (delivered by Dr Lauren Lawson) at the Australasian Society for Autism Research 2020 Conference "*Does mindful awareness mediate the impact of somatic arousal on anxiety or sleep quality?*"

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[18] http://otarc.blogs.latrobe.edu.au/14934-2/

5.3.6 Teaching

Members of the SASLA team have taught into the La Trobe University undergraduate subject Understanding and Support for Autism For example, Dr Lauren Lawson and Dr Rebecca Flower delivered lectures in 2019:

- *Intro to PSY3ASD and a Historical Perspective on autism* (Hudry, K & Flower, R.)
- *Autism in Adolescence/Young Adulthood: Transitioning into independence* (Lawson, L. & Kennedy, L. - Parent, Advocate, Student)
- *Autism in Adulthood: Integration within society at large* (Flower, R., Hofmann, C (employer), & Walton, A.)
- *Autism across the Lifespan: Later-life outcomes and proactive policy* (Flower, R., & Feary, J.)
- *Special Topics: Autism in the brain and body* (Hale, M. & Lawson, L.)

Professor Richdale teaches into the post-graduate Psychology training programs in the subject *Neurobiological and Clinical Disorders in Childhood* (PSY5NBC). She gives the autism lecture.

5.4 Data management

5.4.1 Ethics

The SASLA and ALSAA teams worked closely in the initial development of their surveys so that, as appropriate, there was data overlap enabling both surveys to be combined, and questions covering the age range 15 years to old age at baseline to be asked of the data. This means that researchers from both teams are listed as investigators on both studies. There was continued consultation and further joint additions were made to the surveys, with ethical approval (See Section 3.4.3). We refer to the combined surveys as **CALSA**.

January 2015	SASLA received ethics approval from the La Trobe Human Research Ethics Committee (HEC 14095)
July 2015	The ALSAA study received external ethics approval from the La Trobe HREC.
2016- July 2021	Across the life of the project, we added new staff, research students and OTARC researcher, Dr Darren Hedley, who worked on SASLA or CALSA to SASLA ethics (and ALSAA ethics as appropriate) to ensure we were managing our date according to our ethical approvals.

June 2021	Ethics approval received to extend the ALSAA study for 12-months.
June, 2021	Approval received from the La Trobe HEC for permanent data retention of SASLA from July 1, 2021.

Confidentiality - all SALSA or CALSA data files were provided in a de-identified form (i.e., no email, name, contact details included) to lead researchers approved by the HEC and prepared by staff approved by the HEC. For SASLA and CALSA data files this was the SASLA Research Officer.

5.4.2 CALSA author guidelines and data application management

As a result of our close working relationship with ALSAA, the growth of the data sets, and the need to share data with research students and other members of the Autism CRC, a need for author and data application guideline became necessary to prevent overlap on individual projects within CALSA. This is currently an online process (hosted on REDCap) and managed by the SASLA Research Officer. The data management committee was Professor Trollor, Professor Richdale, and post-doctoral research fellows associated with CALSA at the time of any application. Where an applicant was also a member of this committee they withdrew from all discussions on their application.

This data management plan was created to be in line with:

- SASLA and ALSAA ethics,
- management practices for other data repositories,
- the NHMRC ethical research guidelines,
- Autism CRC authorship and publication guidelines, and
- internal meetings and email exchanges with the Autism CRC in 2016.

As indicated above, de-identified data sets were supplied (through a secure platform) to the lead researcher of an individual project upon its approval.

6. Implications for research and practice

6.1 Clinical practice

Our research utilising SASLA data has resulted in new evidence that can shape the delivery of support for autistic individuals experiencing mental health difficulties.

- Due to the high prevalence across the lifespan of anxiety and depression symptoms, autistic people require **accurate and timely assessment** by clinicians as routine.
- **Mental health and wellbeing** are critical to supporting autistic Australians, especially females, those living alone or with high levels of loneliness, and those with limited social supports.
- Increasing **adaptive emotion regulation strategy use** is likely to positively impact mental health outcomes, regardless of maladaptive strategy use.
- Targeting **psychological flexibility** in autistic adults has the capacity to reduce anxiety and depression symptoms.
- When considering the mental health of autistic adults, **satisfaction with social supports** is more important than the quantity of social supports, while **reducing loneliness** could buffer against suicidal ideation.
- Treating **sleep difficulties** is important for autistic clients; autistic individuals, particularly females, are highly susceptible to sleep difficulties. Better sleep quality is associated with better mental health thus, sleep difficulties may be positively influenced by the treatment of mental health conditions and vice versa.
- Treating both mental health problems and sleep problems may assist in improving **quality of life** and may lead to improved psychological wellbeing for autistic adolescents and adults.
- Both the **HADS and PHQ-9** demonstrate similar properties in autistic adult samples to that of community samples and can be used by clinicians to measure anxiety and depression. The PHQ-9 has been validated in autistic adults aged 15 to 80, the HADS for those 14 to 25 years of age.
- Our newly factorised version of the **Brief COPE** can preliminarily be used to screen coping strategies used by autistic adults.
- When addressing support options for mental health difficulties in the autistic adult population it is important to consider the impact of an individual's coping strategies and resilience.

6.2 Future research directions

Vocation and education

- Further research with larger participant numbers is required to fully understand barriers to post-school activities, particularly employment, and then to determine how to remove them.

Physical and mental health and well-being

- There is a need to develop and trial mental health interventions for autistic adults that focus on a variety of relevant targets, including psychological flexibility (I.e., reducing intolerance of uncertainty) and use of adaptive regulation strategies (I.e., engagement coping, cognitive reappraisal) to manage arousal.
- Emotion regulation strategy use needs further exploration using larger, well-characterised samples with age- and gender-matched control groups to fully capture the variety of emotion regulation strategies used by autistic adults via approaches that can capture contextual information in real time (e.g., observational methods or Experience Sampling Methodology).
- Future research should assess the relationship between emotion regulation strategy use and depressive symptoms via longitudinal designs to determine patterns of causality and identify potential risk factors for depression in autism.
- More needs to be understood about the high suicide risk for autistic people, including predictors and protective factors. This should include autism trait profiles, community engagement, loneliness, availability and quality of social supports, mental health and wellbeing, and sleep quality.
- Further research is necessary to unravel the mechanisms underlying the relationships between flexibility in emotion regulation and psychological well-being for autistic people.
- Given the role of sleep in mental health and optimal daytime functioning, there is a critical need for future research to focus on understanding the cause of poor sleep quality in autism and develop sleep interventions for autistic adults.
- There is an urgent need for the development of more effective intervention options for anxiety and depression for autistic people that are tailored for specific individual profiles, including exploration of intervention approaches that move beyond modifications of Cognitive Behavioural Therapy (CBT) recommended in current autism literature.
- Future research for mental health conditions requires longitudinal or lagged, cross-sectional designs with population level or epidemiologically ascertained data in order to better characterise patterns of change in anxiety and depression symptoms in the autistic

population, the mechanisms underpinning the emergence and maintenance of mental health symptoms, as well as how they cause and/or interact with other co-occurring conditions, in particular sleep and suicidal ideation.

- Given the negative effects of stress on mental health, further research is required regarding coping and resilience in autistic adults.
- Better understanding of the role of autistic traits, in particular sensory sensitivities and restrictive and repetitive behaviours, in the development and maintenance of mental health conditions and sleep quality is needed.

Psychometric validation and scale development

- Clinical tools used to assess symptoms and functioning should be validated for use in autistic populations, or autism-specific tools developed.

Other

- Further research is needed to fully understand factors that influence quality of life for autistic people particularly social and environmental quality of life.
- Further research is required examining service provision experiences with the NDIS across the autism community would be particularly useful in providing feedback and identifying challenges to be addressed. In the Australian context, working alongside families and allowing both caregiver and autistic voices to be heard would be invaluable in understanding the support service barriers they can face, and ultimately improving services.
- Caregivers/parents of older adolescents and autistic adults are also vulnerable to poor mental health and poor sleep quality. Further investigation of the needs of, and supports for caregivers is important given that a significant proportion of autistic adults remain living at home.

7. Key recommendations

This section of the report consolidates SASLA research findings (Section 4), community consultation, and the implications for research and practice (Section 6) into recommendations from the SASLA team.

We make the following recommendations for the improvement of research and practice:

1. A **National Autism Plan** should be developed in consultation with autistic individuals, families, autism organisations, service providers and researchers.
2. The Federal government must commit to **reducing the age of autism diagnosis** so that there are increased opportunities for earlier access to supports for autistic people. Through the provision:
   - Of a national training package for educational, medical, and allied health staff on the early presentation of male and female autistic phenotypes to reduce the age of diagnosis, particularly in girls.
   - Of increased Commonwealth places in relevant clinical degrees to increase the number of qualified diagnosticians leading to improved access to a timely diagnosis.
   - Access to subsidised diagnosis for adolescent and adult referrals.
3. A national **bullying plan** to tackle the pervasive bullying and social exclusion encountered in Australian schools.
4. Develop National guidelines to **increase social inclusion and participation** for autistic people from childhood onwards in education, employment and within the wider community.
   - To be developed with autistic people, autism peak bodies, community groups, service providers and families.
5. Introduce **guidelines for the NDIS** on providing accessible individual/carer supports in the pre-planning stage of applying for NDIS funding for those with autism. To include - detailed explanations and examples of available supports (in their area) and how to best plan an application that addresses both individual and family needs.
6. Governments must urgently provide specialised, accessible and **evidence-based mental health supports** for autistic people and their family/carers.
7. Create **National Training Packages** to increase knowledge and awareness of autism:
   - **For the workplace** - including reasonable workplace adjustments, strategies for supporting individual differences and mental health supports. Disability Employment Service (DES) providers should be included in any training and consultation with autistic adults about their needs and experiences will be paramount.

    - **For mental and physical healthcare service providers -** about the unique clinical presentation of co-occurring conditions in autism and on the appropriate use of validated tools to identify and inform the treatment of these conditions. Developing preventative strategies will also be important. The team notes that in the SASLA age group, physical health is generally less of a concern but, international research indicates that autistic adults are more at risk of physical health conditions than is the general population. Thus, developing preventative strategies would be useful for autistic people in the SASLA age range.
    - **For education providers** to understand how to provide appropriate supports that can assist autistic students to thrive in educational settings.
    - To provide **easy access** to the **best advice** for autistic clients from *all* service providers. This must be developed in consultation with autistic individuals, families, autism organisations, service providers and researchers.

8. Secure and reliable long-term funding for future **autism research** to further support autistic people to improve knowledge about:
    - Barriers and supports required to improve employment and vocational outcomes.
    - Predictors of physical health, mental health, and well-being leading to improved supports and support availability for autistic people.
    - Protective factors that can be targeted by clinicians to buffer risk factors associated with the poor physical and mental health outcomes, and reduced well-being that are so common in autism.
    - Measures of which are valid and reliable for use in autistic populations.
    - How sleep affects mental health and quality of life.
    - Effective preventative and intervention strategies to address the societal and health challenges faced by autistic adolescents and adults.
9. Transition supports:
    - Equip services and develop supports for successful transition of autistic adolescents from school into further education and employment.
    - Provide support and information for parents/carers of autistic youth transitioning from high school into further study and employment.
    - Existing supports must be made more available and accessible for autistic adolescents leaving school and entering a new study/employment environment. For example, work experience initiatives, life skills and independent living courses, access to school councillors, and equity and diversity staff on university and vocational education campuses.

- The 10 recommendations of the Victorian DHS Final report “Supporting transition to and participation in tertiary education for students with an Autism Spectrum Disorder” (Richdale et al., 2012) are still relevant and are supported by SASLA research therefore they should be actioned by government.

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Appendix 1 – Adult Forum

Note: The questions wording was in line with the Autism CRC's language policy

Online survey questions

Are you:

  a. Parent of an individual with ASD;
  b. Individual with ASD;
  c. A relative of an individual with ASD (please specify:______________)
  d. Practitioner/support worker (please specify:_______________)
  e. Other (please specify:_______________)

1. Gender: Male / Female
2. Date of birth (dd/mm/yyyy): _ _/_ _/_ _ _ _

Questions specific to individuals with ASD:

3. How old were you when you were diagnosed with ASD___________
4. Highest level of completed education?

☐ Year 10 high school or equivalent

☐ Year 12 high school or equivalent

☐ TAFE/Certificate or Diploma

☐ Undergraduate Degree

☐ Postgraduate Degree

☐ Other – detail: ____

5. Have you experienced challenges during your education (past or current)?
   a. If yes, what was the greatest challenge you have experienced during your education?
6. What do you think helped you the most during your education?
7. Do you currently have a paid job? Yes / No

    a. If yes, what type of job do you do?
    b. If yes, how many hours a week do you work?

8. Have you ever tried to find employment/job?
    a. If yes, have you experienced challenges in finding employment/job?
        i. If yes, what was the greatest challenge in finding employment/job?
    b. If yes, what do you think helped you the most in finding employment?
9. Have you had a job/employment in the past?
    a. If yes, have you ever experience challenges in keeping your job?
        i. If yes, what was the greatest challenge in keeping your job?
    b. If yes, what do you think helped you the most in keeping your job?
10. What is the greatest challenge you have experienced growing up?

Questions specific to parents/caregivers:

11. How many children do you have?
12. How many of your children have been diagnosed with ASD?
13. Does (any of) your child/children with ASD have intellectual disability? Yes / No
14. Highest level of completed education?

- ☐ Year 10 high school or equivalent
- ☐ Year 12 high school or equivalent
- ☐ TAFE/Certificate or Diploma
- ☐ Undergraduate Degree
- ☐ Postgraduate Degree
- ☐ Other – detail: ____

15. Do you currently have a paid job? Yes / No
    a. If yes, what type of job do you do?
    b. If yes, how many hours a week do you work?

Please complete the following questions for your eldest child with ASD (if you have more than one child diagnosed with ASD)

16. How old was your child when he/she was diagnosed with ASD__________

17. What is your child's highest level of completed education?

☐ Year 10 high school or equivalent

☐ Year 12 high school or equivalent

☐ TAFE/Certificate or Diploma

☐ Undergraduate Degree

☐ Postgraduate Degree

☐ Other – detail: ______________________________________

18. Has your child with ASD ever experienced challenges during his/her education (past or current)?
    a. If yes, what was the greatest challenge experienced during education by your child?

19. What do you think helped your child the most during his/her education?

20. Does your child with ASD currently have a paid job? Yes / No
    a. If yes, what type of job do you do?
    b. If yes, how many hours a week does your child work?

21. Has your child ever tried to find employment/job?
    a. If yes, has he/she experienced challenges in finding employment/job?
        i. If yes, what was the greatest challenge in finding employment/job?
    b. If yes, what do you think helped your child the most in finding employment?

22. Has your child ever had a job/employment in the past?
    a. If yes, has he/she ever experience challenges in keeping his/her job?
        i. If yes, what do you think was the greatest challenge in keeping your child's job?
    b. If yes, what do you think helped your child the most in keeping his/her job?

23. What is the greatest challenge your child has experienced growing up?

Questions for all:

24. At the moment, how do you keep up to date with current information in the area of Autism Spectrum Disorders? Please tick all that apply:

☐ Campaigns;

☐ Information from clinicians/teachers/support workers;

☐ Specialist non-academic professional journals;

☐ Specialist academic research journals (e.g. Journal of Autism and Developmental Disorders or similar);

☐ Conferences and courses;

☐ Newspapers;

☐ Other online news;

☐ Google searches;

☐ Membership of voluntary organization (e.g. Amaze, Alpha Autism, Aspergers Victoria);

☐ Other (Please specify_______________________).

25. What type of information about ASD do you find most difficult to find?

26. What type of information about ASD would you like to hear about from us (researchers)?

27. Which of these options would you prefer as a way of presenting/communicating information about ASD to you (rate by importance).

    ○ Talks/presentations (and how often___________);

    ○ Drop in sessions where you would have a chance to talk with the researcher (and how often_______________);

    ○ Website/blog providing written summaries of research findings;

    ○ Community online forum;

    ○ Webinars on topics of interest to you.

    ○ Other (Please specify_______________________).

Panel Questions

Questions for everyone on the panel:

- What is the greatest challenge you have experienced:
    - Growing up? (individuals with ASD)
    - Raising a child or children diagnosed with ASD? And what do you think was the greatest challenge for your child/children (parents)
    - Working with individuals with ASD? And what do you think was the greatest challenge parents and their child/children (support worker)
- Is anxiety and depression something you experience or have experienced? What was it like for you?
    - Ask parents and support worker about their experiences of anxiety and depression in individuals with ASD.
- What do you worry most about
    - Your future (individuals with ASD)
    - Your child's future (parents)
    - The future of individuals with ASD and their families (support worker)
- Support:
    - How are you currently supported? (individuals with ASD)
    - What do you currently do to support your child? And what support do you receive? (parents)
    - How do you support individuals with ASD? (support worker)
- If you have a chance to give advice to younger individuals diagnosed with ASD, what advice would you give?

Question for just support worker for the end:

- What have you learnt from working with individuals diagnosed with ASD?

Question for just parents on the panel:

- If you knew what you know today with regards to raising a child diagnosed with ASD, what would you do differently?

Appendix 2 – SASLA questionnaires

Baseline demographic questions young adults

These questions help us to learn more about you.

1. Birth Date: ______/______/________ 2. Gender: Male / Female
DD MM YYYY

3. Postcode of where you live: ________________
4. Have you been diagnosed with one of the following? Please select your most recent diagnosis.

☐ Autism Spectrum Disorder
☐ Autistic Disorder
☐ Aspergers Disorder/ Syndrome
☐ High Functioning Autism
☐ PDD-NOS
☐ Other (please describe):
☐ Don't know
☐ None of the above

5. Year of diagnosis (for example 2007):

6. Do you have diagnostic reports for your ASD diagnosis?

☐ Yes ☐ No ☐ Don't know

7. Have you received any interventions or support for your social and communication difficulties or autism spectrum disorder?

☐ Yes ☐ No ☐ Don't know

If Yes, what interventions or supports have you received?

☐ Early intervention
☐ ABA
☐ Integration aid at primary school
☐ Integration aid at high school
☐ Other (please describe):

8. Have you ever been diagnosed with any of the following conditions? Please select all which are applicable for you, you can choose more than one.

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy (please describe):

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe)

9. Do you currently have any of the conditions listed in the question above?

☐ Yes ☐ No

10. What conditions do you currently have? Please select all which are applicable for you, you can choose more than one.

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy (please describe):

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe):

11. Have you ever received treatment for the conditions listed in the question above?

☐ Yes ☐ No ☐ Don’t know

12. What conditions have you received treatment for?

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe):13. In the past 2 weeks, have you taken any of the medications below? If you have, please specify how long you have been taking them for.

Medication type	Yes	No	Medication name	How long have you been taking medication for?
Sleeping tablets or capsules	☐	☐		
Tablets or capsules for anxiety or nerves	☐	☐		
Tranquillizers	☐	☐		
Antidepressants	☐	☐		
Mood stabilisers	☐	☐		
Other medications for your mental health	☐	☐		
None of the above	☐	☐		
Don’t know	☐	☐		

14. Have you had any of these health check-ups and tests during the past 12 months? Please check any that you have had.

☐ Dentist check-up

☐ General health check-up with doctor or GP

☐ Blood test

☐ Cholesterol test

☐ Don't know

☐ Other check-up and tests (please describe):

15. Have you received all the standard vaccines when you were a child?

☐ Yes ☐ No

16. Have you previously taken part in a sleep study?

☐ Yes ☐ No

17. What is your height? (for example: 150 cm)

18. What is your weight? (for example: 60 kg)

19. Do you wear glasses and/or contact lenses?

☐ Yes ☐ No

20. Do you use a hearing aid?

☐ Yes ☐ No

20a. If you use a hearing aid, do you use it on:

☐ One ear

☐ Both ears

21. I live with:

☐ Both parents (mother and father)

☐ One parent only (only mother or only father)

☐ One parent (mother or father) and another carer (please describe):

☐ With another relative (please describe):

☐ Other (please describe):

22. Language(s) spoken at home:

☐ English

☐ Other (please describe):

23. Country of birth:

☐ Australia

☐ Other (please describe):

24. Ethnic background:

☐ Australia

☐ Aboriginal

☐ Torres Strait Islander

☐ Other (please describe):

☐ Do not wish to answer

24. Vocational Index (See Appendix 2 Questionnaire list)

26. What is your highest level of Education (Please tick highest level completed):

☐ Some Primary School

☐ Completed Primary School

☐ Some High School

☐ Completed High School

☐ TAFE Certificate/Diploma

☐ Trade Certificate

☐ University, Undergraduate Studies

☐ University, Post Graduate Studies

If you have completed high school, please complete the following questions.

26a. Did you receive any support when you were transitioning out of school (or leaving school)?

☐ Yes ☐ No ☐ Don't know

If you have answered Yes, please briefly describe the supports you received for transitioning out of school.

If you have answered Yes, in your opinion, were the supports you received for transitioning out of school sufficient?

☐ Yes ☐ No

If you have answered No, Would you have liked to receive support for transitioning out of school?

☐ Yes ☐ No

26b. If you did not receive any support for transitioning out of high school, please describe the types of supports that you think you would have liked to receive for transitioning out of school.

27. Do you currently study at high school, TAFE, university or community college?

☐ Yes ☐ No

If you have answered No, skip to question 28.

27a. I am currently studying at:☐ Home only (not going to school)

☐ High school

☐ Special School

☐ TAFE

☐ University

☐ Online course

☐ Other (please describe):

27b. If you are studying at high school, what year level are you in?

☐ Year 10

☐ Year 11

☐ Year 12

☐ Other (please describe):

27c. If you are studying at TAFE or university, what is the name of your course?

27d. What is the name of the school or institution you are studying at?

27e. What is the qualification you will achieve when you complete your course?

☐ High school

☐ Certificate II -TAFE

☐ Certificate III - TAFE

☐ Certificate IV -TAFE

☐ Diploma - TAFE

☐ Bachelor's degree

☐ Master's degree

☐ PhD

☐ Other (please specify):

27f. I am studying:

☐ Full time ☐ Part time

27g. How well do you get along with other students and teachers at school last year?

	Well	Not well	Bad	Didn't interact	Don't know
Get along with students	☐	☐	☐	☐	☐
Get along with teachers	☐	☐	☐	☐	☐

27h. What do you think about your school?

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
I enjoy school	☐	☐	☐	☐	☐
I like my teachers	☐	☐	☐	☐	☐
I like my classmates	☐	☐	☐	☐	☐
School is challenging	☐	☐	☐	☐	☐

27i. Has any of the following ever happened to you in the school?

	Yes	No	Don't know
Held back a grade in school	☐	☐	☐
Suspended from school (including in-school suspensions)	☐	☐	☐
Expelled from school	☐	☐	☐
Had things stolen from a locker, desk, or other places at school	☐	☐	☐
Been bullied or picked on by other students or made to do things like give them money at school or on the way to or from school	☐	☐	☐
Been physically attacked or involved in fights at school or on the way to or from school	☐	☐	☐
Been teased or called names at school	☐	☐	☐

27j. Using a number between 0 and 100, what was your average grade for the last academic term? (<dates>)

27k. How many days of classes did you miss last academic term? (<dates>include days you were unable to attend classes due to illness)

27l. During the past school year, did you take part in any of the following kinds of activities?

	Yes	No	Don't know
Lessons or classes outside of school in things like art, music, dance, a foreign language, religion, or computer skills	☐	☐	☐
School activities outside of class, such as sports teams, band or chorus, school clubs, or any other	☐	☐	☐
Volunteer or community work	☐	☐	☐
Social activities, such as birthday parties or going over to their home	☐	☐	☐
A school-sponsored work activity, like a work-study job, an internship, or a school-based business	☐	☐	☐
Work for pay that is not work around the house or a school-sponsored work activity	☐	☐	☐
Out-of-school group activity (please describe): ______________________	☐	☐	☐

28. Are you currently employed or have a job?

☐ Yes ☐ No.

If you have answered No, skip to question 29.

28a. What is your job or occupation? (For example: cashier, paper delivery, volunteer)

28b. What are your main tasks and duties?

28c. What kind of business or service is carried out by your employer in the place where you work?

28d. What is the name of your employer? If you don't know or do not want to answer, you don't have to answer this question.

28e. How satisfied or happy are you with your job?

1 Very unhappy/unsatisfied	2	3	4 Fairly happy/satisfied	5	6	7 Very happy/satisfied
☐	☐	☐	☐	☐	☐	☐

29. Are you looking for work or a job?

☐ Yes. ☐ No.

If you have answered Yes, answer questions 29a to 29f and skip questions 29g and 29h.

If you have answered No, skip questions 29a to 29f and answer questions 29g and 29h.

29a. At any time during the last 4 weeks have you been looking for full-time or part-time work?

☐ Full-time work ☐ Part-time work

29b. Any time in the last 4 weeks, have you done any of these? Please select all which are applicable for you, you can choose more than one.

☐ Written, phoned or applied in person to an employer for work

☐ Answered an advertisement for a job

☐ Looked in newspapers

☐ Checked factory notice boards, or used the touch screens at Centrelink offices

☐ Been registered with Centrelink as a job seeker

☐ Checked or registered with an employment agency

☐ Advertised or tendered for work

☐ Contacted friends/relatives to ask about potential jobs

☐ Other (please describe):

29c. How many jobs have you applied for in the last 3 months?

29d. Have you been able to find work or a job?

☐ Yes ☐ No

If No, why do you think you have not been successful in finding work?

29e. If you had found a job, could you have started work last week?

☐ Yes ☐ No ☐ Maybe ☐ Don't know

29f. If you were offered a job, could you start work in the next 4 weeks?

☐ Yes ☐ No ☐ Don't know

29g. Even though you are not looking for work, would you like a full-time or part-time job?

☐ Yes ☐ No ☐ Don't know

29h. What are all the reasons you are not looking for work or a job now?

☐ I am studying right now

☐ I do not want to work

☐ I have health problems

☐ I am too young to work

☐ I don't have enough skills or experience to find a job

☐ Don't know

30. Have you ever had a part-time or casual job?

☐ Yes ☐ No

31. Please indicate whether or not you have received a support in the areas described below. If you have not received support, please indicate how much you know about these areas.

	Have you received support		**How much do you know about**		
	Yes	**No**	**Know a little**	**Know a lot**	**Don't know**
Funded programs that are available specifically for young people with disability after school	☐		☐	☐ ☐ ☐	
How to get career advice	☐	☐	☐	☐	☐
Study options after school e.g. TAFE, University	☐		☐	☐ ☐ ☐	
Supports that are available for people young people with disability in TAFE and universities	☐	☐	☐	☐	☐
Services that can help young people with disability find jobs	☐		☐	☐ ☐ ☐	
Apprenticeships and Traineeships	☐	☐	☐	☐	☐
Payments from the Federal Government to assist young people e.g. Disability Support Pension, Youth Allowance	☐		☐	☐ ☐ ☐	
How to find and make new friends after leaving school	☐	☐	☐	☐	☐

Romance and dating (for example, where to find potential partners, how to tell is someone is interested in you)	☐	☐	☐	☐	☐
Sex education (for example, contraception, safe sex and sexual health, sex and romantic touching)	☐	☐	☐	☐	☐
Getting a license	☐	☐	☐	☐	☐
Using public transport to get from one place to another (for example, planning trips, travel cards)	☐	☐	☐	☐	☐
Cooking simple meals	☐	☐	☐	☐	☐
Managing money (for example, internet banking, paying bills)	☐	☐	☐	☐	☐
Managing health (for example, healthy eating, exercising, making medical appointments, taking medication)	☐	☐	☐	☐	☐

Baseline demographic questions Parents/carers

These questions help us to learn more about you.

1. Birth Date: ______/______/________ 2. Gender: Male / Female

DD MM YYYY

3. Postcode of where you live:

4. Language(s) spoken at home:

☐ English ☐ Other (please describe):

5. Country of birth:

☐ Australia ☐ Other (please describe):

6. Ethnic background:

☐ Australia ☐ Other (please describe):

☐ Aboriginal ☐ Do not wish to answer

☐ Torres Strait Islander

7. For the child you are completing this survey for, what is his/her specific diagnoses? Please select one.

☐ Autism Spectrum Disorder

☐ Autistic Disorder

☐ Aspergers Disorder/ Syndrome

☐ High Functioning Autism

☐ PDD-NOS

☐ Other (please describe):

8. Year of diagnosis (for example 2007):

9. Do you have diagnostic reports for your child's ASD diagnosis?

☐ Yes ☐ No

10. Has your child received any interventions or support for his/her social and communication difficulties or autism spectrum disorder?

☐ Yes ☐ No

If Yes, what interventions or supports has your child received? Please select all which are applicable for your child, you can choose more than one.

☐ Early intervention

☐ ABA

☐ Integration aid at primary school

☐ Integration aid at high school

☐ Other (please describe):

11. Has your child ever been diagnosed with any of the following conditions? Please select all which are applicable for your child, you can choose more than one.

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy (please describe):

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe):

12. Does your child currently have any of the conditions listed in the question above?

☐ Yes ☐ No

13. What conditions does your child currently have? Please select all which are applicable for your child, you can choose more than one.

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy (please describe):

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe):

14. Have your child ever received treatment for the conditions listed in the question above?

☐ Yes ☐ No

15. What conditions have your child received treatment for?

☐ Anxiety

☐ Depression

☐ Obsessive compulsive disorder (OCD)

☐ Speech or language impairment

☐ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)

☐ Cerebral palsy

☐ Asthma

☐ Allergy

☐ Hearing impairment (deafness)

☐ Seizure disorder (epilepsy)

☐ Visual Impairment (low vision)

☐ Tuberous sclerosis

☐ Other (please describe):

16. In the past 2 weeks, has your child taken any of the medications below? If your child has taken medications, please specify how long he/she has been taking them for.

Medication type	Yes	No	Medication name	How long have you been taking medication for?
Sleeping tablets or capsules	☐	☐		
Tablets or capsules for anxiety or nerves	☐	☐		
Tranquillizers	☐	☐		
Antidepressants	☐	☐		
Mood stabilisers	☐	☐		
Other medications for your mental health	☐	☐		
None of the above	☐	☐		

17. Have you received all the standard vaccines when you were a child?

☐ Yes ☐ No

18. Have you previously taken part in a sleep study?

☐ Yes ☐ No

19. We would like to know more about your daughter's/son's language. Please select all which are applicable for your child, you can choose more than one.

Expressive language

☐	**No speech or sounds**
☐	Babbles, gurgles, coos or laughs without meaning
☐	Babbles or makes noises with meaning
☐	Gives names of people or things when asked
☐	Spontaneously says names of several familiar objects for some purpose
☐	Says phrases of two words
☐	Says some longer phrases, missing out small linking words (when time go holiday?)
☐	Talk in spontaneous sentences using small linking words
☐	Uses past, present and future tenses and complex sentences

Receptive language

☐	**Responds to name only**
☐	Understands simple phrases in context (clean the room, go to bed)

☐	Understands and responds appropriately to a phrase not said regularly
☐	Can be sent out of the room to fetch 2 or more objects (e.g. go upstairs and get your hat and shoes)
☐	Understands a sequence of instructions (e.g. first put your paints away and then wash your hands)
☐	Understands instructions, which involve decisions (e.g. see if your hat is in the cupboard if it isn't then have a look upstairs)

20. What is your relationship to the child:

☐ Mother

☐ Father

☐ Other (please specify):

21. What is your highest level of Education (Please tick highest level completed):

☐ Some Primary School

☐ Completed Primary School

☐ Some High School

☐ Completed High School

☐ TAFE Certificate/Diploma

☐ Trade Certificate

☐ University, Undergraduate Studies

☐ University, Post Graduate Studies

22. What is your usual Occupation/Profession?

☐ Manager

☐ Professional

☐ Technician

☐ Teacher

☐ Community/Personal Service Worker

☐ Clerical and Administrative Worker

☐ Sales Worker

☐ Machinery Operator and/or Driver

☐ Labourer

☐ Other (please describe):

☐ Do not wish to answer

23. Current employment status

☐ Working full-time

☐ Working part-time

☐ Unemployed

☐ On maternity/paternity leave

☐ Home carer or home duties

☐ Student

☐ Retired/Pensioner

☐ Other (please describe):

Questionnaire list

Questionnaires	**Autistic and non-autistic**			**Autistic with an ID**			**Parent/Carer**		
	T1	**T2**	**T3**	**T1**	**T2**	**T3**	**T1**	**T2**	**T3**
Autism Characteristics									
The Autism Quotient – Short (Hoekstra et al., 2011). A 28-item scale assessing autistic traits in individuals without an intellectual disability.	▨		▨	▨		▨	▨		▨
The Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A) (Barrett et al., 2015). A 20-item self-report measure of restricted and repetitive behaviours (RRB) suitable for adults.	▨	▨	▨	▨	▨	▨	▨		▨
The Glasgow Sensory Questionnaire (Robertson et al., 2012). A 42-item scale measuring common sensory signs and symptoms associated with autism.	▨			▨					▨
The Intolerance of Uncertainty Scale- 12 (Carleton et al., 2007). A 12-item scale measuring tolerance to uncertainty in terms of prospective and inhibitory anxiety.	▨	▨	▨				▨	▨	▨
The Impact of Diagnosis Scale-Preliminary Revision (Arnold et al., 2020). Designed to measure the experience of receiving an autism diagnosis. ***Note***: *A longer version of this scale was added to develop a robust IODS for autism.*			▨						
Health									
The Composite Autonomic Symptom Score – 31 (Sletten et al., 2012). A 31-item scale, which measures autonomic symptom severity.	▨		▨	▨		▨	▨		▨
Pittsburgh Sleep Quality Index (Buysse et al., 1989). A 10-item scale measuring sleep difficulty.	▨	▨	▨	▨	▨	▨	▨	▨	▨
Flinders Fatigue Scale (Gradisar et al., 2007). A 7-item scale measuring frequency and severity of fatigue.	▨	▨	▨	▨	▨	▨	▨	▨	▨
Mental health									
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (Lebeau, et al., 2012). A 10-item scale that measures the level of anxiety experienced by an individual.	▨	▨	▨	▨	▨	▨	▨	▨	▨
DSM-5 Dimensional Anxiety Scales: Social Anxiety Disorder-Adult (Lebeau, et al., 2012). A 10-item scale that measures the level of social anxiety experienced by an individual.			▨			▨			▨
Obsessive-Compulsive Inventory – Revised (OCI-R) (Foa, et al., 2002). An 18-item scale assessing the symptoms of Obsessive Compulsive Disorder (OCD).	▨		▨	▨		▨	▨		▨
Penn State Worry Questionnaire (Meyer et al., 1990). A 16-item scale that measures the occurrence, intrusiveness and pervasiveness of worry.	▨						▨		
The Patient Health Questionnaire-9 (Kroenke et al., 2001). A 9-item scale measuring occurrence and severity of depressive symptoms.	▨	▨	▨	▨	▨	▨	▨	▨	▨
Hospital Anxiety and Depression Scale (Zigmond et al., 1983). A 14-item scale that detects states of depression and anxiety.	▨	▨	▨	▨	▨	▨			

Questionnaires	Autistic and non-autistic			Autistic with an ID			Parent/Carer		
	T1	T2	T3	T1	T2	T3	T1	T2	T3
The Warwick Edinburgh Mental Well-being Scale (Tennant et al., 2007). A 14-item scale, which measures mental well-being.	▨	▨	▨				▨	▨	▨
The Brief COPE (Carver, 1997). A 28-item scale measuring coping strategy.	▨						▨		▨
Emotion									
General Positive Affect (PANAS-X) (Thompson, 2007). A 10-item scale that measures negative affect.	▨			▨			▨		
The Emotion Regulation Questionnaire (Gross et al., 2003). A 10-item scale that measures the ability of an individual to regulate emotions.	▨	▨	▨	▨	▨	▨	▨	▨	▨
Developmental Behaviour Checklist-Adolescent/Adult version Revised (Mohr et al., 2011). Assessment of behavioural and emotional problems of adults.									A
Adult temperament Questionnaire (Evans et al., 2007). Effortful Control Scale Subscales; activation, attentional and inhibitory control. Negative Affectivity Scale Subscales; discomfort and frustration.	▨			▨			▨		
Mindful Attention Awareness Scale (Brown et al., 2003). A 5-item scale designed to measure a state of mind where one simply observes what is taking place and is aware of the present (mindfulness) – state version.	▨						▨		
Interpersonal Reactivity Index (Davis, 1983). A 21-item scale that measuring 3 aspects of empathy including; perspective taking, empathic concern and personal distress.	▨						▨		
Levels of Emotional Awareness Scale (Barchard, et al. 2011). A 5-item scale measuring levels of emotional awareness.	▨								
Retrospective Behavioural Inhibition Scale (Gladstone et al., 2005). An 18-item scale assessing childhood memories of exhibiting inhibition to the unfamiliar.	▨			▨			▨		
Big-Five Factor Marker – Factor 1 (Goldberg, 1992). A 10-item scale that measures surgency or extraversion.	▨			▨			▨		
Waisman Activities of Daily Living Scale (Maenner et al., 2013). A 17-item scale measuring an individual's independence in daily living activities.							A	A	A
Sternberg's Adaptive Behaviour Checklist (Sternberg et al., 1981). A 41-item scale measuring aspect of intelligence including; Practical Problem-Solving Ability, Verbal Ability and Social Competence subscales.	▨						▨		

Questionnaires	Autistic and non-autistic			Autistic with an ID			Parent/Carer		
	T1	T2	T3	T1	T2	T3	T1	T2	T3
Relationships & Social Networks									
UCLA Loneliness Scale (Russell, 1996). An 8-item scale that measures levels of loneliness.	●		●				●	●	●
The Social Support Questionnaire-6 (Sarason et al., 1987). A 6-item scale measuring social support including number of people who support you in a situation and how satisfied you are with that support.	●		●				●		●
Satisfaction with Love Scale (Neto, 2005). A 5-item scale measuring love life satisfaction.			●						●
The Retrospective Bullying Questionnaire (Schäfer, et al, 2004). 44-item measure assessing the frequency, seriousness, and duration of bully victimization in primary and secondary school; bully-related psychological trauma, suicidal ideation if bullied, and bullying in college and the workplace.			●			●			
Social Well-being Scale (Keyes, 1998). A 6-item scale measuring social integration and social contribution.	●								
Activities, Participation & Quality of Life									
World Health Organisation Quality of Life Assessment (Harper, 1998). A 26-item scale that measures quality of life.	●	●	●	●	●	●			●
Vocational Index for Adults with Autism (Taylor et al., 2012). A 10-item measures the vocational activities of individuals on the autism spectrum (modified for Australian context).	●	●	●	●	●	●			
International Physical Activity Scale (IPAQ-S) (Booth, 2000). assesses the types of intensity of physical activity and sitting time that people do as part of their daily lives.			●			●			●
Caring									
Positive Affect Index (Bengston et al., 1993). A 10-item scale that reflects a parent's feelings toward their child.							●		●
Caregiver Activity Survey (McCarron et al., 2002). A 6-item scale that measures caregiver burden including time spent providing care.							●	●	●

Note. T1: Baseline; T2: 1-year follow-up; T3: 2-year follow-up; A: Parent/carer answering about adult with autism; Questionnaires in blue are not in ALSAA; Autistic participants with co-occurring intellectual disability were informant-report.

Appendix 3 – Sex and gender questions

1. What sex were you assigned at birth?

- ☐ Male
- ☐ Female
- ☐ Intersex/indeterminate/unknown

2. What is your current gender identity? (Check all that apply)

- ☐ Male
- ☐ Female
- ☐ Trans male/Trans man
- ☐ Trans female/Trans woman
- ☐ Genderqueer/Gender non-conforming
- ☐ Different identity (please state): ____

3. Have you been diagnosed with one of the following? Please select your most recent autism diagnosis.

- ☐ Autism Spectrum Disorder
- ☐ Autistic Disorder
- ☐ Aspergers Disorder/ Syndrome
- ☐ High Functioning Autism
- ☐ PDD-NOS
- ☐ Other (please describe): ____
- ☐ Don't know
- ☐ None of the above

Appendix 4 – COVID-19 questions

Has the COVID-19 pandemic affected any of the following aspects of your life?		Please describe the impact this has had
Caused you to experience a mental health issue. E.g., stress, anxiety, depression	Yes/No	
Made any existing mental health issue worse	Yes/No	
Caused you to experience physical health difficulties	Yes/No	
Made any existing physical health difficulties worse	Yes/No	
Disrupted your ability to sleep if you had good sleep prior to the pandemic	Yes/No	
Made any exiting sleep difficulties (E.g., insomnia) worse	Yes/No	
Altered the type and dosage of any medications taken prior to the COVID 19 pandemic	Yes/No	
Altered the frequency of health check-ups. E.g., dentist, General health check-up with doctor or GP, blood tests	Yes/No	
Employment. E.g., lost your job, been stood down, reduced hours	Yes/No	
Ability to look for a job	Yes/No	
Access to day programs	Yes/No	
Ability to study at university	Yes/No	
Ability to study at TAFE or community college	Yes/No	

Appendix 5 - Peer-reviewed publications

Peer-reviewed papers using SASLA survey data

2017

1. **Uljarević, M., Richdale, A.L.,** Evans, D.W., **Cai, R.Y.,** & Leekam, S.R. (2017). Interrelationship between insistence on sameness, effortful control and anxiety in adolescents and young adults with autism spectrum disorder (ASD). *Molecular Autism, 8,* 36. https://doi.org/10.1186/s13229-017-0158-4 *This article is open access.*

2018

2. **Cai, R.Y., Richdale, A.L.,** Dissanayake, C., & **Uljarević, M.** (2018). Brief report: Inter-relationship between emotion regulation, intolerance of uncertainty, anxiety, and depression in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48,* 316-325. https://doi.org/10.1007/s10803-017-3318-7
3. **Cai, R.Y., Richdale, A.L.,** Foley, K-R., Trollor, J., & **Uljarević, M.** (2018). Brief report: Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders, 45,* 1-8. https://doi.org/10.1016/j.rasd.2017.10.002
4. Hedley, D., **Uljarević, M.**, Foley, K-R., **Richdale, A.,** & Trollor, J. (2018). Risk and protective factors underlying suicidal ideation in autism spectrum disorder. *Depression and Anxiety, 63,* 652. https://doi.org/10.1002/da.22759
5. **Uljarević, M., Richdale, A.L.,** McConachie, M., Hedley, D., **Cai, R.Y.,** Merrick, H., Parr, J. R., Le Couteur, A. (2018). The Hospital Anxiety and Depression Scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research, 11,* 258-269. https://doi.org/10.1002/aur.1872

2019

6. **Cai, R.Y., Richdale, A.L.,** Dissanayake, C., Trollor, J., **Uljarević, M.** (2019). Emotion regulation in autism: Reappraisal and suppression interactions. *Autism, 23*(3):737-749. https://doi.org/10.1177/1362361318774558
7. **Flower, R.L.,** Sadka, N., **Richdale, A., & Haschek, A.** (2019). The Australian context: Commentary on 'Mothers' experiences of the transition of young people with autism spectrum disorder to adult care' (McMinn, Schulz & Ludlow, 2019), and 'Challenging the status quo:

Commentary on Mothers' experiences of the transition of young people with autism spectrum disorder to adult care' (Beadle-Brown & Roberts, 2019). *Research and Practice in Intellectual and Developmental Disabilities, 6*(2), 147-153. https://doi.org/10.1080/23297018.2019.1652928

2020

8. Arnold, S.R.C., Huang, Y., Hwang, Y.I. (Jane), **Richdale, A.L.,** Trollor, J.N., & **Lawson, L.P.** (2020). "The Single Most Important Thing That Has Happened to Me in My Life": Development of the Impact of Diagnosis Scale—Preliminary Revision. *Autism in Adulthood, 2*(1), 34-41. https://doi.org/10.1089/aut.2019.0059
9. Arnold, S., **Uljarević, M.,** Hwang, Y. I., **Richdale, A. L.,** Trollor, J. N., & **Lawson, L. P.** (2020). Brief Report: Psychometric Properties of the Patient Health Questionaire-9 (PHQ-9) in Autistic Adults. *Journal of autism and developmental disorders, 50*(6), 2217–2225. https://doi.org/10.1007/s10803-019-03947-9
10. **Flower, R.L., Richdale, A.L. & Lawson, L.P.** (2020). Brief Report: What Happens After School? Exploring Post-school Outcomes for a Group of Autistic and Non-autistic Australian Youth. *Journal Autism and Developmental Disorders, 24*(4), 954-967. https://doi.org/10.1007/s10803-020-04600-6
11. **Jovevska, S., Richdale, A.L., Lawson, L.P., Uljarević, M.,** Arnold, S.R.C., and Trollor, J. N. (2020). Sleep Quality in Autism from Adolescence to Old Age. *Autism in Adulthood, 2*(2), 152-162. https://doi.org/10.1089/aut.2019.0034
12. **Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J.,** Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism, 24*(4), 954-967. https://doi.org/10.1177/1362361320908107
13. **Sahin, E.,** Bury, S., **Flower, R., Lawson, L., Richdale, A,** Hedley, D. (2020). Psychometric Evaluation of an Australian Version of the Vocational Index for Adults with Autism. *Autism in Adulthood, 2(*3), 185-192. https://doi.org/10.1089/aut.2019.0060
14. **Uljarević, M.,** Hedley, D., Rose-Foley, K., Magiati, I, **Cai, R. Y.,** Dissanayake, C., **Richdale, A.L.,** Trollor, J. (2020). Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. *Journal of autism and developmental disorders, 50(9), 3155–3165.* https://doi.org/10.1007/s10803-019-04084-z

2021

15. **Muniandy, M., Richdale, A.L.,** Arnold S.R.C., Trollor, J.N., & **Lawson, L.P**. (2021). Factor Structure and Psychometric Properties of the Brief COPE in Autistic Adults. *Research in Autism Spectrum Disorders*, *48*, 101764. https://doi.org/10.1016/j.rasd.2021.101764
16. **Muniandy, M., Richdale, A.,** Arnold, S., Trollor, J., & **Lawson, L.** (2021). Inter-relationships between Trait Resilience, Coping Strategies and Mental Health Outcomes in Autistic Adults. *Autism Research*. https://doi.org/10.1002/aur.2564
17. **Chetcuti, L., Richdale, A. L., Haschek, A, Uljarević, M., & Lawson L. P**. (Submitted April 2021). Discrete effortful control skills moderate relations between childhood behavioural inhibition and mental ill-health in autistic youth. Under review.
18. **Flower, R. L., Lawson, L. P., Haschek, A., Cai, R. Y., Uljarević, M., & Richdale, A. L.** (submitted November 2020). Health status and service use of transition-age autistic youth in Australia: The Study of Australian School Leavers with Autism (SASLA). Under review.
19. Huang, Y., Hwang, J., Arnold, S. R. C., **Lawson, L. P., Richdale, A. L.,** & Trollor, J. N. (Submitted May 2021). Short report: Autistic adults' experiences of diagnosis disclosure. Under review.
20. **Muniandy, M., Richdale, A.,** Arnold, S., Trollor, J., & **Lawson, L.** (Submitted December 2020). Associations between Coping Strategies and Mental Health Outcomes in Autistic Adults without Intellectual Disability. *Autism*. Under review.

Other peer-reviewed papers by the SASLA team

2016

1. Evans, D.W., Michael, A.M., **Uljarević, M.,** Lusk, L.G., Buirkle, J.M., & Moore, G.J. (2016). Neural substrates of a schizotypal spectrum in typically-developing children: Further evidence of a normal-pathological continuum. *Behavioral Brain Research, 315,* 141-146. doi 10.1016/j.bbr.2016.08.034
2. Hedley, D., Brewer, N., Nevill, R., **Uljarević, M.,** Butter, E., & Mulick, J. A. (2016). The relationship between clinicians' confidence and accuracy, and the influence of child characteristics, in the screening of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46,* 2340-2348. doi 10.1007/s10803-016-27669
3. Hedley, D., Nevill, R., **Uljarević, M.,** Butter, E., & Mulick, J. A. (2016). ADOS-2 Toddler and Module 1 standardized severity scores as used by community practitioners. *Research in Autism Spectrum Disorders, 32,* 84-95. doi 10.1016/j.rasd.2016.09.005
4. Newbigin, A., **Uljarević, M.,** Vivanti, G., & Dissanayake, C. (2016). Brief report: Empathic responsiveness of high functioning children with autism to expressed and anticipated distress.

Journal of Autism and Developmental Disorders, 46, 33383343. doi 10.1007/s10803-016-2862-x

5. Ozturk, Y., Vivanti, G., **Uljarević, M.,** Dissanayake, C., & Team, V. A. (2016). Treatment related changes in children's communication impact on maternal satisfaction and psychological distress. *Research in Developmental Disabilities, 56,* 128-138. doi 10.1016/j.ridd.2016.05.021
6. **Uljarević, M.,** Katsos, N., Hudry, K., & Gibson, J.L. (2016). Practitioner review: Multilingualism and neurodevelopmental disorders – an overview of recent research and discussion of clinical implications. *Journal of Child Psychology and Psychiatry, 57*, 1205-1217. doi 10.1111/jcpp.12596

2017

7. Evans, D.W**., Uljarević, M.,** Lusk, L.G., Loth, E., & Frazier, T. (2017). Development of two dimensional measures of restricted and repetitive behavior in parents and children. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*, 51-58. doi 10.1016/j.jaac.2016.10.014
8. Hedley. D., Cai, R., **Uljarević, M.,** Wilmot, M., Spoor, J. R., **Richdale, A.,** & Dissanayake, C. (2017). Transition to work: Perspectives from the autism spectrum. *Autism, 22*(5), 528-541. doi 10.1177/1362361316687697
9. Hedley, D., **Uljarević, M.,** Cameron, L., Halder, S., **Richdale, A.,** Dissanayake, C. (2017). Employment programs and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism, 21*(8), 929-941. doi 10.1177/1362361316661855
10. Hedley, D., **Uljarević, M.,** Wilmot, M**., Richdale, A.,** & Dissanayake, C. (2017) Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 47*, 3669-3677. doi 10.1007/s10803-017-3274-2
11. Magiati, I., Lerh, J. W., Hollocks, M. J., **Uljarević, M.,** Rodgers, J., McConachie, H., & Simonoff, E. (2017). The measurement properties of the Spence children's anxiety scale-parent version in a large international pooled sample of young people with autism spectrum disorder. *Autism Research, 10*, 1629-1652. doi 10.1002/aur.1809
12. **Uljarević, M.,** & Evans, D.W. (2017). Relationship between repetitive Behaviour and fear Across normative development, autism spectrum disorder, and down syndrome. *Autism Research, 10,* 502-507. doi 10.1002/aur.1674
13. **Uljarević, M.,** Hedley, D., Alvares, G.A, Varcin, K.J., & Whitehouse, A.J.O. (2017) Relationship between early motor milestones and severity of restricted and repetitive

behaviors in children and adolescents with autism spectrum disorder. *Autism Research, 10,* 1163-1168. doi 10.1002/aur.1763

14. Varcin, K. J., Alvares, G.A., **Uljarević, M.,** & Whitehouse, A.J.O. (2017). Prenatal maternal stress events and phenotypic outcomes in autism spectrum disorder. *Autism Research, 10,* 1866-1877. doi 10.1002/aur.1830

2018

15. Alvares. G.A., Dawson, P.A., Dissanayake, C., Eapen, V., Gratten, J., Grove, R., Henders, A., Heussler, H., **Lawson, L.,** Masi, A., Raymond, E., Rose, F., Wallace, L., Wray, N.R., Whitehouse, A.J.O. (2018). Australian Autism Biobank team. Study protocol for the Australian autism biobank: an international resource to advance autism discovery research. *BMC Pediatr. 18*(1), 284. doi: 10.1186/s12887-018-1255-z. PMID: 30149807; PMCID: PMC6112136.
16. **Cai, R.Y., Richdale, A.L., Uljarević, M.,** Dissanayake, C., & Samson, A.C. (2018). Emotion regulation in autism spectrum disorder: Where we are and where we need to go. *Autism Research.* https://doi.org/10.1002/aur.1968
17. **Halim, A.T**., **Richdale, A.L., & Uljarević, M.** (2018). Exploring the nature of anxiety in young adults on the autism spectrum: A qualitative study. *Research in Autism Spectrum Disorders, 55,* 25-37. doi 10.1016/j.rasd.2018.07.006
18. Hedley, D., **Uljarević, M.,** Wilmot, M., **Richdale, A.,** & Dissanayake, C. (2018). Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders, 46,* 1–7. doi 10.1016/j.rasd.2017.11.003
19. Hickey, M., **Lawson, L.P.,** Marino, J.L., Keelan, J.A., Hart, R. (2018). Relationship between umbilical cord sex hormone binding globulin, sex steroids, and age at menarche: a prospective cohort study. *Fertil Steril. 110*(5), 965-973. doi: 10.1016/j.fertnstert.2018.06.008.
20. **Lawson, L.,** Joshi, R., Barbaro, J., & Dissanayake, C. (2018). Gender differences during toddlerhood in autism spectrum disorder: A prospective community-based longitudinal follow-up study. *Journal of Autism and Developmental Disorders, 48*(8), 2691-2628. doi 10.1007/s10803-018-3516-y
21. Su, X, **Cai, R. Y., & Uljarević, M**. (2018). Predictors of mental health in Chinese parents of children with autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders, 48*, 149-1168. doi 10.1007/s10803-017-3364-1

2019

22. Arnold, S., Foley, K., Huang, Y. I., **Richdale, A., Uljarevic, M., Lawson, L., Cai, R. Y.,** Falkmer, T., Falkmer, M., Lennox, N., Urbanowicz, A., Trollor, J. (2019). Cohort profile: The

Australian Longitudinal Study of Adults with Autism (ALSAA). *BMJ Open, 9*(12). http://dx.doi.org/10.1136/bmjopen-2019-030798

23. **Cai, R.Y., Richdale, A.L.,** Dissanayake, C., & **Uljarević, M.** (2019). Resting heart rate variability, emotion regulation, psychological wellbeing and autism symptomatology in adults with and without autism. *International Journal of Psychophysiology, 137,* 54-62. doi 10.1016/j.ijpsycho.2018.12.010
24. Dissanayake, C., Searles, J., Barbaro, J., Sadka, N., **Lawson, L.P.** (2019). Cognitive and behavioral differences in toddlers with autism spectrum disorder from multiplex and simplex families. Autism Res. 12(4), 682-693. doi: 10.1002/aur.2074. *Autism research, 12*(4), 682–693. https://doi.org/10.1002/aur.2074
25. **Flower, R.,** Hedley, D., Spoor, J.R., & Dissanayake, C. (2019). An alternative pathway to employment for autistic job-seekers: a case study of a training and assessment program targeted to autistic job candidates. *Journal of Vocational Education and Training,* 407-428. https://doi.org/10.1080/13636820.2019.1636846
26. **Lawson, L.P.** (2019). Sex Differences in Autism Spectrum Disorders Across the Lifespan. *Current Developmental Disorder Reports 6,* 57–66. https://doi.org/10.1007/s40474-019-00164-y
27. **Flower, R.,** Dickens, L., & Hedley, D. (2019). Barriers to employment for individuals with Autism Spectrum Disorder: Perceptions of autistic and non-autistic job candidates during a simulated job interview. *Journal of Intellectual Disability Research, Special Issue: Future4All, 63*(7). https://doi-org.ez.library.latrobe.edu.au/10.1111/jir.12652

2020

28. **Cai, R.Y., Richdale, A.L.,** Dissanayake, C., **Uljarević, M.** (2020). How Does Emotion Regulation Strategy Use and Psychological Wellbeing Predict Mood in Adults with and Without Autism Spectrum Disorder? A Naturalistic Assessment. *Journal Autism and Developmental Disorders, 50*(5), 1786-1799. https://doi.org/10.1007/s10803-019-03934-0

2021

29. Yap, C.X., Alvares, G.A., Henders, A.K…**Lawson, L.** (2021). Analysis of common genetic variation and rare CNVs in the Australian Autism Biobank. *Molecular Autism 12.* https://doi.org/10.1186/s13229-020-00407-5

Appendix 6 – Conference presentation outputs

Conference presentations oral

2014

1. **Cai, R. Y. & Richdale, A.** Invited Keynote: *Transition issues and support for students with ASD attending TAFE and University.* CEAV Conference, Melbourne, Victoria.

2015

2. **Richdale, A.** Invited talk: *Supporting young people with autism in tertiary education.* Asia Pacific Autism Conference, Brisbane, Australia. http://www.apac15.org.au/34-speakers/122-amanda-richdale-1
3. **Uljarević, M., Cai, R.Y. & Richdale, A.** *Predicting anxiety in parents of adolescents and young adults with autism spectrum disorders: the contribution of parental individual characteristics, coping styles and levels of social support.* Amaze Autism Spectrum Disorder Research Forum, Melbourne, Australia.
4. **Uljarević, M., Cai, R.Y. & Richdale, A.** Predicting anxiety in parents of adolescents and young adults with autism spectrum disorder: the contribution of parental individual characteristics, coping styles and levels of social support. Asia Pacific Regional International Meeting for Autism Research, Shanghai, China.

2016

5. **Cai, R. Y., Richdale, A. L., & Uljarević, M.** *The relationship between habitual emotion regulation, anxiety, and depression in adolescents and adults on the autism spectrum.* World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
6. **Cai, R. Y., Richdale A., & Uljarević, M.** *Education and employment outcomes of an Australian cohort of young adults on the autism spectrum*. Australasian Society of Autism Research, Perth, Australia.
7. Foley, K., **Uljarević, M., Richdale, A.,** & Trollor, J. *Self-reported QoL of Autistic Adults Living in Australia compared to Non-Autistic Adults.* International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress, Melbourne, Australia.

8. Foley, K., **Uljarević, M., Richdale, A.,** & Trollor, J. *Autism symptoms are not associated with self-reported quality of life for adults on the autism spectrum in Australia.* Australasian Society for Autism Research conference, Perth, Australia.
9. Hedley, D., Dissanayake, C., **Richdale, A.,** Spoor, J., & **Uljarević, M.** *Long-term benefits of supported employment for adults with autism spectrum disorder.* Journal of Intellectual Disability Research, 60, 679. doi 10.1111/jir.12305 IASSIDD World Conference
10. **Richdale, A. & Uljarević, M.** Symposium presentation: *Does Intolerance of Uncertainty Contribute to Insomnia Symptoms in Young People with Autism?* International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) World Congress, Melbourne, Australia.
11. **Richdale, A.** Invited talk: *Core Program 3 Update: Autism CRC Adult Research Program: Finding a place in society*. http://www.amaze.org.au/uploads/2016/09/VAC-CP3-Richdale.pdf Autism CRC Panel, Victorian Autism Conference, Melbourne, Victoria. (http://www.amaze.org.au/events-home/vac/vac-2016-presentations/)
12. **Richdale, A., Uljarević, M.,** Foley, K. & Trollor, J. *Does intolerance of uncertainty contribute to insomnia symptoms in adults on the autism spectrum?* Australasian Society for Autism Research conference, Perth, Australia.
13. **Uljarević, M., Cai, R. Y.,** Hedley, D., Foley, K. R., & **Richdale, A.** *Autism spectrum disorder in adulthood.* Symposia at the International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress, Melbourne, Australia.
14. **Uljarević, M., Cai, R. Y.,** Hedley, D., Foley, K. R., Trollor, J., Lennox, N., Urbanomiz, A., & **Richdale, A.** *Mental health and wellbeing of adolescents and adults with autism and their parents.* Symposia at the Australasian Society for Autism Research Conference, Perth, Australia
15. **Uljarević, M., Cai, R.Y. & Richdale, A.** *Sources of individual variability in well-being of parents of adolescents and young adults with autism.* Australasian Society for Autism Research conference, Perth, Western Australia.

2017

16. Hedley, D. & **Uljarević, M.** *Mechanisms underlying depression and self-harm in adults with autism.* Australasian Society for Autism Research Inaugural state conference, Melbourne, Victoria.
17. **Lawson (Né Hollier), L. & Richdale, A.** *School and Job Satisfaction among Young People on the Autism Spectrum.* Australasian Society for Autism Research. Inaugural state conference, Melbourne, Australia.

18. **Richdale, A, & Uljarevic, M.** *Exploring the role of arousal in predicting sleep problems in youth and young adults with ASD.* Symposium: L McLay, A Richdale, S Jin and K France, Sleep and Interventions in young people with autism spectrum disorders. World Sleep Congress, Prague, Czech Republic.
19. **Richdale, A. & Uljarevic, M.** *Arousal and the prediction of insomnia symptoms in young people on the autism spectrum.* Australasian Society for Autism Research, Inaugural state conference, Melbourne, Victoria.

2018

20. **Cai, R. Y., Richdale, A., & Uljarević, M.** *Patterns of cognitive reappraisal and expressive suppression use and relationship with psychological wellbeing in youth on the autism spectrum: A cluster analysis approach.* International Meeting for Autism Research, Rotterdam, Netherlands.
21. **Haschek. A., Lawson, L., Uljarevic, M., Flower, R., & Richdale, A.** *Baseline Characteristics of the Longitudinal Study of Australian School Leavers with Autism.* Australasian Society for Autism Research, Gold Coast, Queensland.
22. **Lawson L. P., Richdale A. L. & Cai R. Y.** *Gender Differences in Internalising Psychopathology among Young Adults on the Autism Spectrum.* Journal of Intellectual Disability Research 62, 669. https://doi.org/10.1111/jir.12512
23. **Richdale, A.** L. Invited symposium. *Mental Health and Autism Spectrum Disorder: Predicting depression symptoms among adolescents on the spectrum.* International Conference on Child and Adolescent Psychopathology (ICCAP), Malaysia.

2019

24. **Haschek, A., Flower, R., Lawson, L., Uljarevic, M., Cai, R., & Richdale, A.** *Baseline Characteristics of the Longitudinal Study of Australian School Leavers with Autism*. Asia Pacific Autism Conference, Singapore.
25. Hedley, D., Uljarevic, M., Foley, K-R., **Richdale, A. L.,** & Trollor, J. *Risk and protective factors underlying suicidality in autism spectrum disorders.* The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.
26. **Richdale, A.,** Morris, E., Denny, K., & **Lawson, L.** *Addressing insomnia in autistic adults: A pilot study.* 31st Annual Scientific Meeting (ASM) of the Australasian-Sleep-Association and the Australasian-Sleep-Technologists-Association (Sleep DownUnder).
27. **Richdale, A.** Invited symposium. *Clinical and circadian aspects of poor sleep quality.* International Society for Autism Research meeting, May, Montreal, Canada.

2020

28. **Lawson, L., Wong, L., Haschek, A., & Richdale, A. L.** *Does mindful awareness mediate the impact of somatic arousal on anxiety or sleep quality?* Australasian Society for Autism Research 2020 Conference (Online).
29. **Lawson, L.** Invited. *Conducting online longitudinal research.* Judith Lumley Methods Club, online.

2021

30. **Richdale, A. L.** Invited. *Sleep and autism.* Dutch National Autism Conference, Utrecht (Online March 2021).

Posters

2015

1. **Cai, R.Y., Uljarević, M., & Richdale, A.** *The relationship between habitual emotion regulation, anxiety, and depression in adolescents and young adults with autism spectrum disorders.* Asia Pacific Regional International Meeting for Autism Research, Shanghai, China.
2. **Cai, R. Y., Uljarević, M., & Richdale, A. L.** *Emotion regulation as a predictor of depression in adolescents and young adults with autism spectrum disorders.* Asia Pacific Regional International Meeting for Autism Research, Shanghai, China.

2016

3. **Cai, R. Y., Uljarević, M., & Richdale, A. L.** *The relationship between habitual emotion regulation, anxiety, and depression in adolescents and young adults on the autism spectrum*. International Meeting for Autism Research, Baltimore, USA.
4. **Richdale, A., Cai, R., & Uljarević, M.** *Predictors of poor sleep quality in youth and young adults on the autism spectrum.* International Meeting for Autism Research, Baltimore, USA.
5. **Uljarević, M., Cai, R., & Richdale, A.** *Predictors of somatic problems in parents of adolescents and young adults with autism.* International Meeting for Autism Research, Baltimore, USA.

2017

6. **Cai, R. Y., Richdale, A., & Uljarević, M.** *Effects of emotion regulation and intolerance of uncertainty on anxiety and depression in adolescents and young adults with autism.* International Meeting for Autism Research, San Francisco, USA
7. Hedley, D., **Uljarević, M.,** Wilmot, M., Spoor, J., **Richdale, A. L.,** Dissanayake, C. *Self-reported suicidal ideation, depression and loneliness in adults with autism spectrum disorder.* International Meeting for Autism Research, San Francisco, USA.
8. **Richdale, A. L., Lawson, L. P., & Uljarević, M.** *Predicting poor sleep quality in young adults on the autism spectrum.* International Meeting for Autism Research, Rotterdam, Netherlands.
9. **Richdale, A. L., Uljarević, M., Cai, R. Y.** *Predicting insomnia in young adults: The role of autism symptom severity, sensory atypicality and intolerance of uncertainty.* International Meeting for Autism Research, San Francisco, USA.
10. **Uljarević, M., Richdale, A. L., Cai, R. Y.** *Inter-Relationship Between Insistence on Sameness, Effortful Control and Anxiety in Adolescents and Young Adults with Autism Spectrum Disorder.* International Meeting for Autism Research, San Francisco, USA.
11. **Uljarević, M., Richdale, A. L., Cai, R. Y.** *Predictors of Anxiety in Parents of Adolescents and Young Adults with autism spectrum disorder.* International Meeting for Autism Research, San Francisco, USA.

2018

12. Hedley, D., **Uljarević, M.,** Foley, K. R., **Richdale, A. L.,** Trollor, J. *Mechanisms underlying thoughts of self-harm and depression in autism spectrum disorder: Findings from a nationally representative sample.* International Meeting for Autism Research, Rotterdam, Netherlands.
13. **Lawson, L. & Richdale, R.** *Factors associated with post-secondary school independence among young Australians on the autism spectrum.* International Meeting for Autism Research, Rotterdam, Netherlands.
14. Sahin, E., **Lawson, L. & Richdale, A.** *Are sleep and mental health associated with vocational independence in young people on the autism spectrum*. Australasian Society for Autism Research Conference.
15. **Uljarević, M.,** Hedley, D., Rose-Foley, K., Magiati, I., **Cai, R-Y.,** Dissanayake, C., **Richdale, A.,** & Trollor, J. *Anxiety and depression from adolescence to old age in autism spectrum disorder.* International Meeting for Autism Research, Rotterdam, Netherlands.

2019

16. **Flower, R., Richdale, A., &** Arnold, S. *Job Seeking Experiences of Autistic and Non-Autistic Youth.* International Society for Autism Research Annual Meeting.

2020

17. Dissanayake, C., Christou, G. & **Lawson, L.** *Early Developmental Trajectories of Children with Autism from Multiplex and Simplex Families.* In International Society for Autism Research 2020 virtual. Online: International Society for Autism Research.
18. **Jovevska, S., Lawson, L. Richdale, A.,** Trollor, J., & Arnold, S. *Sleep quality and the autism spectrum from mid-adolescence to old age.* Australasian Society for Autism Research Conference
19. **Haschek, A., Flower, R., Richdale, A., Uljarevic, M., Cai, R., & Lawson, L.** *Trait Emotional Awareness in Autistic Adolescents and Young Adults.* In International Society for Autism Research 2020 virtual. Online: International Society for Autism Research. https://insar.confex.com/insar/2020/meetingapp.cgi/Paper/33860
20. **Muniandy, M., Richdale, A. L,** Arnold, S. Trollor, J., & **Lawson, L.** *Factor Structure and Psychometric Properties of the Brief COPE in Autistic Adults.* Abstract accepted for the International Society for Autism Research (INSAR). https://us15.admin.mailchimp.com/campaigns/show?id=1552758
21. **Muniandy, M., Richdale, A. L, & Lawson, L.** *Associations between coping strategies and mental health in autistic adults.* ASfAR Conference 2020, online.
22. **Muniandy, M., Richdale, A. L, & Lawson, L.** *Inter-relationship between resilience, coping strategies and mental health in autistic adults.* ASfAR Conference 2020, online.

2021

23. **Richdale, A. L., Lawson, L., Haschek, A., Hayward, S., Abdullahi, I.,** & Morris, E. (2021). *The Role of Fatigue and Social Wellbeing in Depressive Symptomatology in Autistic Older Adolescents and Young Adults.* Poster presented at International Society for Autism Research (INSAR) Annual Meeting, Virtual, May.
24. Hedley, D., den Houting, J., Hayward, S., Uljarević, M., Bury, S. M., **Lawson, L.,** Clapperton, **A., Haschek,** A., Dissanayake, C., Robinson, J., Trollor, J., & Stokes, M. A. (2021). *The buffering hypothesis of suicide risk in young autistic adults: Does mental wellbeing buffer the effect of depression on suicidal ideation?* Poster presented at the International Society for Autism Research Annual Meeting, Virtual, May 3-7.
25. Huang, Y., Arnold, S., Foley, K-R., **Lawson, L., Richdale, A**., & Trollor, J. (2021). *Predictors of age at diagnosis in a community sample of Australian adults*. Poster presented at the International Society for Autism Research Annual Meeting, Virtual, May 3-7.

Appendix 7 – Other media, publications, presentations and resources

2015

1. **Richdale A.** Invited. *Autism and comorbid conditions.* The Second Child Development and New Knowledge Workshop, Kunming Children's Hospital, Kunming China**.**
2. **Richdale, A., Uljarević, M., & Cai, R. Y.** Invited professional development. *Autism co-morbid conditions and transition from school to work or tertiary studies.* Half-day Professional Development session at Eastern Ranges School, Ferntree Gully, Melbourne, Australia.
3. **Uljarević, M.** *Stress and anxiety in adolescents with ASD.* Living with Autism podcast by La Trobe University (available free on iTunes) or here.
4. **Uljarević, M.** *Ask an autism researcher: Stress and anxiety in adolescents with ASD.* http://otarc.blogs.latrobe.edu.au/stress-and-anxiety-in-adolescents-with-asd/

2016

5. Dissanayake, C., **& Richdale, A.** Invited. *'Autism: Disability or Ability?'* Public session in The La Trobe Bold Thinking Series. Melbourne, Australia. https://www.youtube.com/watch?v=ojwsDvMEdTY
6. **Richdale, A.** *Adults with autism.* Colloquium, RMIT University, Melbourne, Australia
7. **Richdale, A.** *Study of Australian School Leavers with Autism recruitment page.* http://otarc.blogs.latrobe.edu.au/an-update-on-the-autism-crc-longitudinal-study-of-school-leavers-with-autism/
8. **Uljarević, M., Richdale, A., Cai, R. Y.** Invited. *Mental health and well-being of parents of individuals with autism.* Aspergers Victoria Support Group: Melbourne, Australia.

2017

9. **Hollier, L.** Invited. Session Chair: *Perspectives on early identification and intervention. Community perspectives on autism research.* Olga Tennison Autism Research Centre (OTARC), Melbourne, Australia.
10. **Richdale, A.** Adults with autism: What do we know and what are the implications for psychology? *InPsych, 39*. Australian Psychological Society. https://www.psychology.org.au/inpsych/2017/april/richdale

11. **Richdale, A.** Invited. Autism across the lifespan. Hawthorn University of the Third Age. Melbourne, Australia.
12. **Richdale, A.** Invited. Seminar. *Sleep Difficulties in Autism Across the Lifespan: Why be Concerned?* Department of Psychiatry, Royal Melbourne Hospital: Melbourne, Australia.
13. **Richdale, A.** Invited professional development. *What do we know about adults with autism and what are the implications for psychologists?* Colloquium, Cairnmillar Institute, Melbourne, Australia
14. **Richdale, A.** Invited. *Why sleep is important?* La Trobe University's third year Hallmark students, Melbourne, Australia.
15. Smith, A, **Richdale, A,** Trollor, J, & Urbanowicz, A. *Collaborative mental health care to support adults on the autism spectrum.* Mental Health Professionals Network (mhpn) webinar. https://www.mhpn.org.au/webinar-program/Webinars/One-Off/2017/June/Collaborative-mental-health-care-to-support-adult
16. **Uljarević, M., Cai, R. Y., & Richdale, A.** Invited. *Destination unknown. Transition to adulthood for people with autism spectrum disorder.* Seminar, Holmesglen TAFE, Melbourne, Australia.
17. **Uljarević, M.** Invited. *Should we be anxious about anxiety in Autism Spectrum Disorder.* University of Southern California, USA.

2018

18. **Cai, R., & Lawson, L.** *Emotion Regulation and mental Health in individuals on the Autism Spectrum.* Facebook video. Views: 358 **Haschek, A., Lawson, L., & Richdale, A. L.** *Longitudinal Study of Australian School Leavers with Autism: Baseline characteristics.* In La Trobe University Research Showcase.
19. **Haschek, A.** *SASLA baseline snapshot* poster presentation at the Best Practice for Children with Autism: Community Information Session, Bendigo.
20. **Lawson, L. & Haschek, A.** Invited. *Research opportunities for people on the autism spectrum.* Specialisterne, Melbourne, Australia.
21. **Lawson, L.** Invited. *Research opportunities for people on the autism spectrum.* Specialisterne, Melbourne, Australia.
22. **Lawson, L.** *Validating an Anxiety and Depression Scale for Individuals on the Autism Spectrum.* Facebook video. Views: 328 https://www.facebook.com/125312223997/videos/10157068580378998
23. **Richdale, A. L.** Spectrum: Deep dive*. Ask me first: What self-assessments can tell us about autism*. https://www.spectrumnews.org/features/deep-dive/ask-first-self-assessments-can-tell-us-autism/

24. **Richdale, A. L.** Invited *Asperger's and Sleep*. Asperger's Victoria, Melbourne.
25. **Richdale, A. L.** Invited *Sleep and Autism.* Autism Interest Group in Victoria for Speech Pathologists, Melbourne.

2019

26. **Lawson, L.** *Insomnia Intervention for Autistic Adults.* Facebook video. https://www.facebook.com/125312223997/videos/252522212401488
27. **Flower, R**. Summary video presentation of publication Flower, R.L., Sadka, N., Richdale, A., & Haschek, A. *The Australian context: Commentary on 'Mothers' experiences of the transition of young people with autism spectrum disorder to adult care' (McMinn, Schulz & Ludlow, 2019), and 'Challenging the status quo: Commentary on Mothers' experiences of the transition of young people with autism spectrum disorder to adult care' (Beadle-Brown & Roberts, 2019).* Research and Practice in Intellectual and Developmental Disabilities. https://www.tandfonline.com/doi/full/10.1080/23297018.2019.1652928
28. **Flower, R., Haschek, A., & Richdale, A.** *Transitioning youth with autism: longitudinal Study of Australian School Leavers with Autism (SASLA).* Invited professional development. Southern Higher Education Disability Network – Professional Development Day 'Sharing Strategies for Supporting Students'.
29. **Flower, R. L., Haschek, A., Lawson, L. P., & Richdale, A. L.** *Study of Australian School Leavers with Autism (SASLA): Longitudinal Profile 2019.* Olga Tennison Autism Research Centre (OTARC), La Trobe University, Melbourne. https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years
30. **Flower, R.** L. *Study of Australian School Leavers with Autism (SASLA): Baseline profile.* Autism CRC Adulthood webinar. https://www.autismcrc.com.au/news/webinars/adulthood-webinar-2019-26-april-2019
31. **Flower, R. L., Haschek, A., Lawson, L. P., & Richdale, A. L.** *Study of Australian School Leavers with Autism (SASLA): Parent-Carer Baseline Profile Snapshot 2019.* Melbourne, Victoria: La Trobe University. https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years
32. **Haschek, A., Lawson, L., Richdale, A.** *SASLA research directions survey results.* https://sway.office.com/UUXGdbaBWEPkbtT1?ref=Link
33. **Haschek, A., & Flower, R. L.** *Study of Australian school leavers with autism (SASLA): Baseline profile 2018.* Poster presentation at La Trobe University's Open Day, Bundoora.

34. **Haschek, A**. Interview with autistic La Trobe placement student Josh Vartuli *‘Being part of the final product’ – a student’s perspective.* Blog post, OTARC, La Trobe University. [*http://otarc.blogs.latrobe.edu.au/14934-2/*](http://otarc.blogs.latrobe.edu.au/14934-2/)
35. **Lawson, L.P., Haschek, A., & Richdale, A.L.** *Study of Australian school leavers with autism (SASLA): Baseline profile 2018.* Olga Tennison Autism Research Centre (OTARC), La Trobe University, Melbourne. https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years
36. **Lawson, L.** *Family matters in autism outcomes.* Fresh science competition, Melbourne.
37. **Richdale, A., Haschek, A., Flower, R.** *Sleep and young autistic adults pamphlet.* doi 10.26181/60592c32bd800 https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years
38. **Richdale, A.L., Lawson, L., Flower, R., Haschek, A., & Muniandy, M.** *Project 3.016: Comprehensive and Unique Profile of Australian School Leavers with Autism (SASLA) progress presentation to the Autism CRC Board.*

2020

39. **Haschek, A., Richdale, A., Lawson, L**. (2020). SASLA's contribution to the Australian Select Committee on Autism. https://sway.office.com/NWXy6fTEzKHHe4hU?ref=Link
40. **Lawson, L.** *Autism and gender.* ASfAR Institute: Autism and Intersectionality 2020 webinar series.
41. **Richdale, A. L.** Professional development. *Sleep and Autism.* Australasian Sleep Association, Sleep Health Council.
42. **Richdale, A.** L. *Autism and age.* ASfAR Institute: Autism and Intersectionality 2020 webinar series.
43. **Richdale, A.** L. Professional development. *Co-occurring Conditions in Autism: Insomnia, Mental Health and Well-being.* Mental Health Super Summit.
44. **Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I.** *Supporting mental health: What young Australian autistic adults tell us.* Melbourne, Victoria: La Trobe University. doi 10.26181/5fdc10c56879a
45. **Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I.** *Supporting mental health: What young Australian autistic adults tell us (online presentation).* Melbourne, Victoria: La Trobe University. doi 10.26181/5fdc132dc39a8 https://sway.office.com/8lt8IxNRZepuMCFd?ref=Link

46. **Richdale, A.L., Haschek, A., Lawson, L.P., Hayward, S.M., & Abdullahi, I.** *Anxiety, depression and autistic adults (online presentation).* Melbourne, Victoria: La Trobe University. doi 10.26181/5fdc0dd2ec841 https://sway.office.com/zDMNO8GzStVfJJqs?ref=Link
47. **Richdale, A.L., Haschek, A., Lawson, L.P., Hayward, S.M., & Abdullahi, I.** *Anxiety, depression and autistic adults (printable pamphlet).* Melbourne, Victoria: La Trobe University. doi 10.26181/5fdc0c5939471 (342KB)

2021

48. **Richdale, A.** *All Things Sleep.* Life on the Spectrum Podcasts. https://www.buzzsprout.com/1443478/7330606
49. **Richdale, A.** *Sleep and Autism.* Autism Spectrum Australia (Aspect) Podcasts https://www.autismspectrum.org.au/about-autism/podcasts

Appendix 8 - Contributions to policy

2019

1. **Richdale, A., Haschek, R., & Flower, R.** *The Longitudinal Study of Australian School Leavers with Autism's (SASLA) response to the Royal Commission into Victoria's Mental Health System.* https://rcvmhs.vic.gov.au/submissions

2020

2. Dissanayake, C., **Richdale, A. L., Haschek, A.,** Ihsen, E., Barbaro, J., Hedley, D., Bury, S., **Flower, R., Hayward, S. M.,** Sadka, N., Denham, M. *La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Select Committee on Autism.* Bundoora. La Trobe University. (views: 578, downloads:132) https://doi.org/10.26181/5f20f14745abe
3. **Haschek, A., Richdale, A., Lawson, L., Abdullahi, I., Flower, R.,** Unwin, K., Hedley, D., & Bury, S. (2020). *The Longitudinal Study of Australian School Leavers with Autism's (SASLA) response to the inquiry into access to TAFE for learners with a disability Victoria, Australia* La Trobe. https://doi.org/10.26181/5f890479948c5 (views:540, downloads:152)
4. **Richdale, A. L.,** Dissanayake, C., **Haschek, A.,** Ihsen, E., Hedley, D., Bury, S., **Flower, R., Hayward, S. M.,** Denham, M. *La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Education and Employment Legislation Committee: Comment on the Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020's potential impact on autistic higher education students.* Bundoora. La Trobe University. (views: 435, downloads: 129) https://doi.org/10.26181/5f585f483a2e2

2021

5. **Richdale, A. L., Haschek, A. & Chetcuti, L.** (2021). *Feedback on the Productivity Commission Report on Mental Health*. Olga Tennison Autism Research Centre, La Trobe University, Melbourne.
6. **Richdale, A.L.,** Hedley, D., **Haschek, A., Chetcuti, L.,** Radovini, A., Saunders, F., Ball, R., Bury, S., Mantzalas, J., Fisher, C.A., Stokes, M., **Lawson, L.P.,** & Morris, E. (2021). La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Select Committee on Mental Health and Suicide Prevention. Bundoora. La Trobe University. doi 10.26181/605914d9aabe4

7. Richdale, A.L., Haschek, A. (2021). Comment on the Draft National Preventive Health Strategy 2021-2030. Bundoora. La Trobe University.

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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