



AutismCRC

Longitudinal Study of Australian School Leavers with Autism (SASLA)

EXECUTIVE SUMMARY

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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.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, 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.

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.

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.

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



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