

We Belong Too: The experiences, needs and service requirements of adolescents with autism spectrum disorder

An Autism Spectrum Australia (Aspect) funded, developed and implemented research project

Key Aspect personnel: Susan Bruck, Susanna Baldwin, Debra Costley and Anthony Warren

Background

Autism spectrum disorder (ASD) is a lifelong developmental disability characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours, and sensory sensitivities.

The word 'spectrum' is used because the range and severity of the difficulties people with ASD experience can vary widely.

This research project innovatively surveyed adolescents with ASD who are at the higher functioning end of the spectrum with the aim of developing a profile of their life experiences, aspirations and their future support needs.

The study also independently surveyed parents of adolescents with ASD at the higher functioning end of the spectrum.

The findings from this study demonstrate that adolescents with ASD aged between 12-17 years of age need more support in the school classroom, managing bullying and discrimination, coping with stress and making friends.

The outcomes from the parent survey reported a shortage of coordinated, appropriate and affordable ASD-specific support services. The study also identified the adolescent and parent concerns for the future.

The findings predict that in the longer-term, the adolescents will need ongoing support with finding and managing employment, and independent living.

The word 'spectrum' is used because the range and severity of the difficulties people with ASD experience can vary widely.

The Study

Anonymous online and paper-based questionnaires were used to independently survey the adolescents (aged 12-17 years) and the parents. The questions in the parent survey closely reflected the questions in the adolescent survey. The ethics approved survey was advertised widely through the Aspect website, social media and promoted directly to schools and autism-specific organisations throughout Australia.

Data from the adolescents and parent surveys were not matched. Informed consent survey responses were received from one hundred adolescents and 65 parents between November 2012 and June 2013.

"In some classes the teachers expect me to answer questions that are ambiguous and not specific enough, and that annoys me."

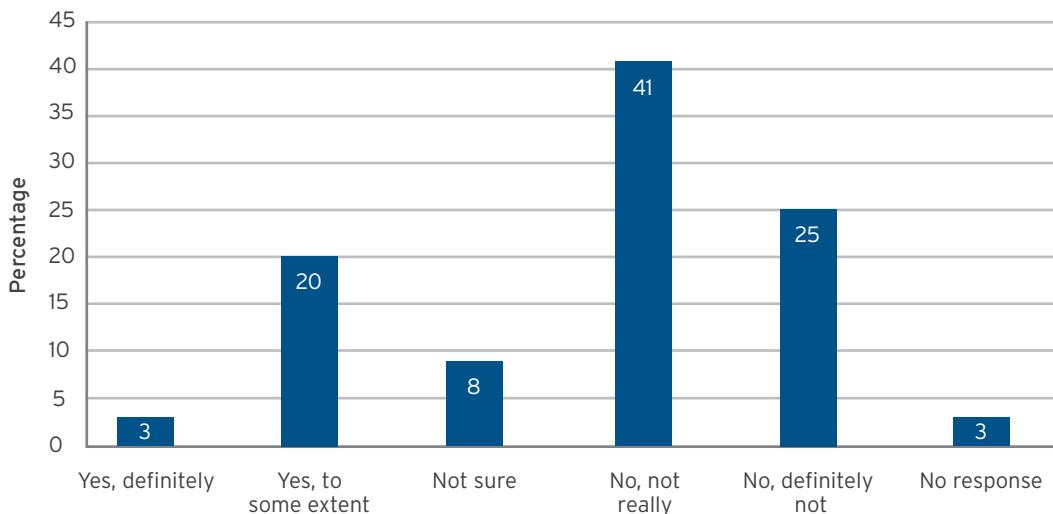
The findings

Education

This research shows that adolescents with ASD need additional educational support.

- 74% of adolescents have difficulty in concentrating in class
- 73% of adolescents need more support preparing for exams
- 66% of adolescents need more support with completing their homework
- 63% of adolescents need more support with school class work
- 62% of adolescents need more support understanding teachers in the classroom
- 66% of parents believe educators are not well-informed about ASD

Are educators well-informed about autism?



Health

There is a need for additional mental health support for adolescents with ASD.

- 69% of adolescents feel lonely
- 66% of adolescents need support managing stress
- 58% of adolescents need more support for bullying and discrimination
- 49% of parents report that their child needs additional support for a mental health condition

Employment

The adolescents want to find a job or study.

- 51% of the school students want to have a part-time job outside of school hours
- 39% of the school students plan to go to TAFE, university or complete training for a specific job
- 24% of the school students plan to get a job after they graduate from school

Parents, however, are concerned that their children are inadequately prepared for employment, and that the community is ill-equipped to provide employment opportunities.

- 50% of parents report their adolescent is not receiving adequate support in preparation for employment
- 43% of parents are concerned that employment agencies are not well-informed about the capabilities and strengths of young people with ASD

Social and Community Activity

Adolescents need additional support to develop their social skills.

- 59% of adolescents need help making friends at school
- 22% of adolescents would like to join an ASD social group, however, long waiting lists prevent joining
- 22% of adolescents would like to join a hobby or sports group

Service Accessibility

Adolescents require additional support for an independent adult life.

This study shows that support services are inaccessible to many families because they are uncoordinated, unaffordable and unsuitable for adolescents with ASD at the higher end of the spectrum.

- 86% of parents report a shortage of practical support
- 75% of parents report a lack of appropriate services in their local area
- 71% of parents report inadequate service coordination
- 66% of parents report professional services are too expensive
- 66% of parents report long waiting lists for professional services
- 65% of parents report a lack of awareness about ASD among support service providers

In addition to the adolescent focus of the research, the study also surveyed the parents' and carers' perceptions about their adolescent's support requirements. It also investigated the needs of parents and carers with an adolescent with ASD at the higher functioning end of the spectrum.

Deficiencies in parent support services were reported in the survey.

- 65% of parents report insufficient case management facilities
- 62% of parents report a shortage of parent counselling services
- 57% of parents report inadequate availability of parental training programs that are relevant to their child's needs
- 54% of parents report a lack of parent support groups

*"My son is rarely invited to social gatherings.
He would love more social opportunities"*

The Future

The adolescents were given the opportunity to write about their aspirations for the future. Employment was the most frequently stated aspiration. Independence in the form of learning to drive, having a car and a home all featured prominently in the responses. Many plan to travel.

Despite their ambitions, the adolescents reported expecting to need support for independent living.

- 55% of adolescents expect to need support with finding a job
- 48% of adolescents expect to need support in acquiring independent accommodation

Conclusions

This report shows that across Australia, adolescents with ASD are often prevented from accessing support facilities due to a shortage of professional services. These services are frequently uncoordinated and typically expensive. Compounding these deficiencies in professional support is the lack of understanding about ASD amongst many support service providers.

For adolescents the lack of coordinated support services can mean reduced educational assistance, increased stress and difficulties gaining employment.

The results from this study reveal that the adolescents in this study are ambitious and aspirational. The adolescents desire to work, study and travel. Independence is their primary goal.

What is clear from this research is that by asking the adolescents what their needs are, we are able to define the support structures that are required to assist them in meeting their aspirations.

The findings from this world-first study should encourage governments and the community at large to increase funding for support services, so that adolescents with ASD can move through education and into employment and the wider community and achieve their full potential.

Recommendations

Education

- » Provide student and practising teachers with relevant information, strategies and training programs about working with students with diverse abilities
- » Deliver supported transitions plans and programs at critical stages in the student's life in conjunction with expert educators, family and community members
- » Provide greater interface between high schools, TAFE, universities and employers
- » Increase funding from government and education departments for adolescents' learning support initiatives

Health

- » Provide more opportunities for the development of community knowledge and skills so that the community can appropriately support people with ASD and mental health issues
- » Promote and support appropriate health management skills for young people with ASD
- » Provide support and training for all professionals who work with adolescents with ASD
- » Appropriately resource primary care professionals so that they can better support people with ASD

Employment

- » Provide appropriate, relevant and supported work experience for students whilst in the education system
- » Provide training for disability support workers in the provision of ASD-specific Transition to Work programs
- » Deliver workplace programs that include support for people with diverse abilities
- » Provide training and support for disability support agencies, case workers and specialist employment providers

Social and Community Activity

- » Support people with ASD to access mainstream social and community activities
- » Provide ASD-specific social clubs so that young people can practice social skills in a safe environment before transitioning to mainstream environments
- » Support age appropriate social skills programs in schools and community groups
- » Provide peer education and facilitate opportunities to make friends at school
- » Provide appropriate community support for parents and carers
- » Improve funding for the provision of a range of support services

The findings from this world-first study should encourage governments and the community at large to increase funding for support services, so that adolescents with ASD can move through education and into employment and the wider community and achieve their full potential.

The Aspect vision for research

Aspect is committed to improving the lives of individuals with ASD through service provision and evaluation for continuous improvement. As the largest ASD-specific service provider in the country and one of the largest in the world, Aspect is well positioned to facilitate and conduct such evaluation. Aspect undertakes and supports research to evaluate Aspect's and other programs, practices and interventions in order to provide improved services and interventions for children and adults with ASD. Aspect also promotes research at state and national levels and facilitates tertiary students' research. As our aim is to develop our knowledge of what can be done to support individuals with ASD, research findings will also make a significant contribution to the field of international research into ASD. Aspect requires ongoing funding to support these key initiatives and is always keen to talk to potential new partners and donors.



For further information please go to the Aspect website
www.autismspectrum.org.au/research

To make a donation to the Aspect Research Program please contact Aspect Relationship Fundraising on 1800 AUTISM (1800 288 476)