

We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism

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

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Background

What was our goal?

We **Belong** was designed to give a public voice to adults with Asperger's disorder (AD) and high functioning autism (HFA) in Australia. It is the first large-scale study in this country to describe in detail the life experiences, aspirations and support needs of this group. Its goal is to raise awareness, promote discussion and pave the way for change regarding the services and supports that are essential to improved outcomes for these adults across a wide range of life domains.

One participant said, *"I often get asked to speak about my past life or strategies for kids, which is of benefit to some, but when I say I want to speak about my needs and my political agenda for Asperger's, then people go quiet all of a sudden. My parents wanted me to communicate and be autonomous when I grew up. Why do so many now want me to be dependent and shut up?"*

My parents wanted me to communicate and be autonomous when I grew up. Why do so many now want me to be dependent and shut up? Brian, aged 49, QLD

What information was collected?

The research team developed a comprehensive survey for adults with AD and HFA. Topics covered included health, education, work, social life, community involvement, and daily living. A corresponding survey for parents of adults with AD and HFA was developed concurrently. The surveys were promoted through Aspect networks and in local, national and online social media.

Over 300 adults with AD and HFA and almost 200 parents, representing every Australian state and territory, participated in the survey.

The findings

Aspirations and goals

Our research confirms that adults with AD and HFA have aspirations and goals for their lives that are similar to those held by many other Australians. Importantly, however, as a group they also wish to be better understood and accepted in society, to have their ability to contribute professionally and socially more clearly recognised, and to be valued rather than stigmatised for their differences. The things that adults with AD and HFA most hope for in the future are to be engaged in **fulfilling employment**, to enjoy good mental and physical health, and to have a range of successful **social relationships**, including if possible a life partner.

Barriers to service access

Narrow eligibility criteria for disability services, as well as cost, location and waiting times, may all serve to hinder adults with AD and HFA from obtaining the professional supports they need. This group not only wants to see services developed that are responsive to their specific needs and challenges, but to receive guidance and help to access and navigate their service options. Sixty per cent of adults in the study stated that they need **support to access professional services**. Almost half of parents identified the cost of professional services as a barrier to their son or daughter obtaining the supports that he or she needs. Half reported frustration with wait list times.

One participant said, *"I think a support group would be good for me and my family. Living in the country means I am isolated and there isn't anything available for me. Services are very limited, outsourced and overstretched."*

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Service expertise and integrity

Notwithstanding their intelligence and capabilities, adults with AD and HFA face a diversity of ongoing support needs that must be recognised for the very real and crippling challenges that they are or can become. This group understandably wants services with appropriate levels of professional knowledge and expertise, who will take seriously their struggles, needs and expectations, treating them with the same respect and understanding as they would any other disability cohort. Over three-quarters of parents reported that when they had been able to access services on behalf of their son or daughter, they detected a **lack of awareness or understanding** of autism among those delivering the service and 70% of parents reported experiences of **poor coordination** between different services.

One participant said, *“services need to be made aware that just because you don't look different or make unusual sounds, you can still be struggling with life enough for others to be able to show some compassion without being condescending and patronising. You don't have to be at the extreme ends of the coping rod - there is a large grey area in between.”*

Services need to be made aware that just because you don't look different or make unusual sounds, you can still be struggling with life... Carol, aged 52, NSW

Health services

Mental health is a significant area of concern for adults with AD and HFA. This group needs services that can deliver better mental health outcomes, including emotion management skills and interventions for co-morbid conditions such as anxiety and depression. Over three-quarters of adult respondents reported that they experience **frequent worry or stress**, and 70% identified as having a **mental health condition**. Only half of the respondents in each group felt that they were currently getting enough support to manage these conditions. It is clear that the scars of childhood **bullying and social isolation** run very deep for this group of adults. When reflecting on the ups and downs of their time in education, over 70 per cent of respondents recalled being bullied, having few or no friends, and/or a pervasive sense of 'not fitting in'. One participant said, *“I was depressed for a long time. To have had access to a skilled psychologist when I was younger, who understands Asperger's, would have been very helpful.”*

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Education

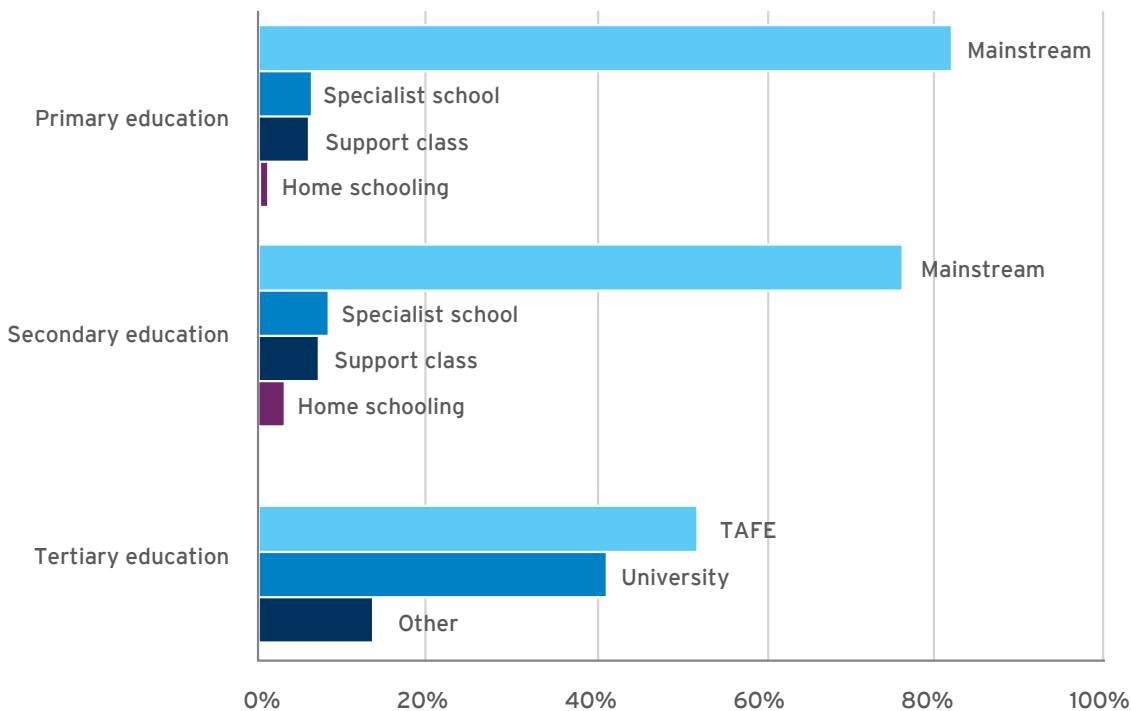
A clear implication of our study findings is that the absence of an intellectual disability does not equate to an absence of learning support needs. Many of today's adults with AD and HFA failed to have these needs properly met while at school, and continue to require support in adult education for issues such as comprehension, organisation and managing an academic workload. In addition, adults rightly expect their educational experiences to be free from bullying and the subsequent years of trauma that result from this.

One participant said, *“I remember every aspect of school as a nightmare. I remember not participating and being assumed to be therefore dumb, and being accused of cheating when handing up complete, original and pristine projects. There was no pleasing them. Why is it abnormal to want to be alone with your own thoughts? Are adjectives and verbs compulsory? Extreme shyness developed and this stopped my career prospects - I became too shy to ask anyone anything.”*

I remember every aspect of school as a nightmare. I remember not participating and being assumed to be therefore dumb, and being accused of cheating when handing up complete, original and pristine projects. Jonathan, aged 34, VIC

Adults with AD and HFA often go through childhood as **keen learners** and continue in this vein into adulthood. Over one-third recalled the enjoyment of learning and studying as one of the best aspects of their time in education. At the time of the survey, more than 80% had commenced or completed a **tertiary qualification**. Notwithstanding their aptitude for study, adults with AD and HFA have experienced significant struggles to reach their full potential in education. Almost half of respondents reported that they received no, or insufficient, additional **support for their learning needs** during their time in education. Many felt that teachers failed to understand their needs and treated them unfairly as a result.

Education settings attended



Employment

Adults with AD and HFA want equitable access to employment opportunities that match their qualifications, strengths and interests. They want employment services and professional organisations to be knowledgeable about autism and willing to implement the supports and strategies that will enable them to perform to their full potential at work.

One participant said, *"I want paid work that utilises my skills and abilities and that I enjoy and derive satisfaction from. There are services for older people, but none specifically for those with Asperger's syndrome. What I need most is a 'mentor' - someone to help me keep my thought processes on track"*

For many, the social demands of the workplace represent a further challenge and an area of extreme vulnerability. In contrast to the Australian national employment rate of 95 per cent, just 54 per cent of the adults with AD and HFA in this study (excluding those still in full-time education) had a **paid job** at the time of completing the survey. Of those adults who are in paid employment, one-third would like to receive more **support at work** related to their autism spectrum disorder. Worryingly almost one-third of a collection of 570 comments about negative experiences in employment spoke of **criticism, ill-treatment and social isolation** in the workplace.

Social supports and services

Contrary to some stereotypes, adults with AD and HFA do not necessarily 'prefer their own company'. Yet in spite of their inherent desire for companionship and social connectedness, many remain isolated, lonely, and painfully conscious of the way in which their struggles with communication and interpersonal relating limit their ability to form meaningful relationships. Notwithstanding their experiences of bullying and isolation, some of respondents' happiest memories of education and the workplace are centred around **friendship, social interaction and collegiality**. However, less than half of the adults in the study reported now having a **regular group of friends**.

One participant said, *"I would like to have some knowledge of basic social skill etiquette so I can be with a group of people comfortably without being selfconscious about making a mistake."*

Around one-third of respondents appealed for better access to **social supports** including mentoring or befriending schemes, organised social groups, and groups centred around common hobbies and interests.

Case management and advocacy

There is an imperative to lift the burden of care for adults with AD and HFA from the shoulders of their parents, many of whom have worked tirelessly throughout their son or daughter's life to support and advocate for them, and are overwhelmed by the anxiety of how their grown child will cope in the event of their parents' deaths. Three-quarters of the parents surveyed stated that they provide at least one form of **regular financial or in-kind support** to their son or daughter and almost half of the adults in the study **lived with their parent(s)**.

Sixty per cent of parents appealed for a **case management** service to help them support their son or daughter; a further 60 per cent expressed a desire for **counselling**; half want more training and half would like the opportunity to join a **parent support group**.

One participant said, *"Services that we source to assist always comment that he's "so high functioning", then they discontinue (after months of seeking help) after a short while, telling him how well he's doing. This then leaves all the caring back to me again."*

The next steps

Data collected from more than 500 respondents has enabled Aspect to describe the lived experiences and unmet needs of a large group of marginalised Australians.

This has occurred at a time when there is strong government and community support for the development of person centred services, as highlighted for example in the NSW Government's Stronger Together report and is also being incorporated in the proposed National Disability Insurance Scheme (NDIS) model, supported by the Australian Government.

This move to a person centred model has particular pertinence for the AD and HFA population, whose highly specific and individualised needs invariably mean that a 'one size fits all' approach to assessment and service provision is not appropriate. The challenge is that people with AD and HFA have not readily qualified for funding under any disability model because by definition they do not have an intellectual disability.

The goal of the **We Belong** study has been to give a voice to a talented, overlooked group of Australians and to raise awareness of their needs with regard to health, education, employment, social and community support; areas which, if addressed, will make an immeasurable difference to many lives.

I hate feeling like I am walking in sand but leave no footprints so there is no evidence I was ever here at all. Alison, aged 44, QLD

One participant said, *"I hate looking stupid. It's the one thing I'm not. I hate having something valuable to say, but no one listens because I can't get it out. I hate feeling like I am walking in sand but leave no footprints so there is no evidence I was ever here at all."*

We Belong provides direction for governments, service providers and communities regarding next steps including new approaches, services and supports that will give this forgotten group of people the recognition and opportunities in society that their talents warrant and their human dignity demands.

The Aspect vision for research

Aspect is committed to improving the lives of individuals with ASDs 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 ASDs. 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 ASDs, research findings will also make a significant contribution to the field of international research into ASDs. 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)