



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

Autism Spectrum Australia (Aspect)  
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# Introduction

**We Belong** is the first large-scale research study in Australia to describe the life experiences, aspirations and support needs of adults who have an autism spectrum disorder (ASD) with no co-occurring intellectual disability. Through a comprehensive body of self-report data, biographical stories and personal reflections, it offers a window into the lives of Australian men and women who experience the daily challenges of a largely invisible, frequently misunderstood, and yet highly complex and nuanced disorder.

## Background

### Nature and prevalence of autism spectrum disorders

Autism is a lifelong developmental disability that impacts on the way a person understands, communicates with and relates to others and the world around them. Recent studies indicate that around one in 100 people has some form of autism, with diagnosis rates acknowledged to be on the rise (Williams et al., 2008).

The clinical term 'Autism Spectrum Disorder' (ASD) encompasses three diagnostic categories, as listed in the current edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-IV; American Psychiatric Association, 1994):

- » Autistic Disorder
- » Asperger's Disorder
- » Pervasive Developmental Disorder - Not otherwise Specified (PDD-NOS).

The clinical identification of ASD is based on a 'triad of impairments', namely:

1. Qualitative impairments in social interaction.
2. Qualitative impairments in communication.
3. Restricted, repetitive and stereotyped patterns of interests, activities and behaviours.

Autistic Disorder (or 'classic' autism) is characterised by marked impairments in all three domains of the triad, with symptoms generally evident prior to three years of age. Asperger's Disorder entails the same core features as Autistic Disorder, but without any significant delay in early language acquisition, cognitive abilities or self-help skills. A diagnosis of PDD-NOS may be applied when an individual presents

with deficits in social interaction and in at least one other area of the triad, but does not meet full criteria for either Autistic Disorder or Asperger's Disorder. For this reason, PDD-NOS is sometimes referred to as 'atypical autism'.

As denoted by the term 'spectrum', autism is a highly heterogeneous disorder, meaning that every individual with an ASD will have a unique profile of strengths and challenges.

Although there is some considerable overlap between autism and intellectual disability, studies have estimated that around 60 per cent of people diagnosed with an ASD have normal or above average intellectual ability (Chakrabarti & Fombonne, 2005). These individuals are often informally described as having 'high functioning autism'. By definition, the majority of people diagnosed with Asperger's Disorder will fall into the 'high functioning' group, and the terms are sometimes used interchangeably.

Although there is some considerable overlap between autism and intellectual disability, studies have estimated that around 60 per cent of people diagnosed with an ASD have normal or above average intellectual ability (Chakrabarti & Fombonne, 2005).

Applying the 'one in 100' autism prevalence rate to the Australian context translates into around 220,000 people nationwide who have an ASD, of whom 60 per cent, or 130,000, can be considered high functioning. Of these, approximately 97,000 are aged 18 years and over.

## Research on adults with autism

Although the autism research field has traditionally been dominated by studies focusing on children, there is now a steadily growing body of literature investigating the presentation, experience and correlates of ASD in adults. Many studies in this area have taken a fairly narrow topic focus or worked with a relatively small number of participants, or both. Notable exceptions include:

- » a UK-wide survey of 237 adults with Asperger's Disorder conducted by researchers at Sheffield Hallam University and covering a broad range of topics, including diagnosis, higher education, employment, accommodation, social life and relationships, the legal system, and mental health (Beardon & Edmonds, 2007);
- » the National Autistic Society's *I Exist* project: a UK-wide survey of over 1,400 adults with autism and their parents, aimed at raising government and public awareness of service and support needs for this group;
- » the Adolescents & Adults with Autism (AAA) study at the University of Wisconsin, which is collecting data from 405 participants over a five-year period, with a particular focus on documenting the challenges and impacts for families supporting a young person or adult with ASD.

In addition, some authors have undertaken large-scale literature reviews in an effort to synthesise research findings across this area: relevant reports include Barnhill (2007), Stuart-Hamilton et al. (2009), and Howlin & Moss (2012).

Together, these studies and reviews have highlighted the vastness and complexity of adult autism as a research field. Some of the key issues that have been explored in this area include:

- » mental health and emotional wellbeing;
- » social participation;
- » barriers to employment;
- » access to and eligibility for services;
- » choice and control over interventions and supports;
- » rights and discrimination.

In the Australian context, these themes have been echoed in state government reports, including *Stronger Together: A New Direction for Disability Services in NSW 2006-2016* and the *Autism State Plan* developed by the Department of Human Services, Department of Education and Early Childhood Development, and Autism Victoria in May 2009.

Priority areas for reform identified in these reports include:

- » social inclusion and participation;
- » services and supports that facilitate, rather than act as barriers to, participation;
- » strengthening the ASD experience of the workforce;
- » specialist support to enhance educational opportunities, including during transition stages;
- » pre-employment and employment support, including workforce capacity building;
- » strategies to effect successful participation in the community.

Together, these studies and reviews have highlighted the vastness and complexity of adult autism as a research field.

*Stronger Together* comments perceptively that individuals with ASD tend to “fall between the cracks of disability service provision”, reflecting a lack of professional understanding about the needs of this group that results in their exclusion from services. It is for this reason that the report identifies an urgent need for “development of a comprehensive evidence base about autism spectrum disorders”.

Most of the studies listed above have profiled adults from across the autism spectrum, including those with profound intellectual impairment and significant support needs. In the light of this, it is important to acknowledge research that suggests if anything, higher functioning adults experience worse outcomes in life than other ASD groups. This is because the consequences of having serious difficulties in social interaction and communication are not compensated for, so much as exacerbated by, a higher intellectual ability and normal language development (Mordre et al., 2011).

To date, no single published research study in Australia has attempted to comprehensively profile the lived experiences of a large sample of adults with high functioning ASD across a wide range of life domains. **We Belong** sought to address this gap by conducting a detailed survey of over 300 adults who have an ASD with no co-occurring intellectual disability, exploring topics such as their health, education, work, social and community activities, and daily life.

Of central importance to this research was its focus on capturing the personal perspectives and stories of adults with AD and HFA, thus giving a unique 'voice' to a group whose needs have not been well understood or documented. These first-person data were complemented with information gathered from the parents of adults with AD and HFA, together with relevant service providers.

*Of central importance to this research was its focus on capturing the personal perspectives and stories of adults with AD and HFA.*

## Overview of the study

In its entirety, the **We Belong** study comprised three complementary arms of data collection:

1. A survey of adults with Asperger's Disorder and high functioning autism.
2. A survey of parents of adults with Asperger's Disorder and high functioning autism.
3. Telephone interviews with service providers who have professional dealings with adults with Asperger's Disorder and high functioning autism.

## Scope and structure of the report

This report presents a comprehensive, though not exhaustive, overview of the findings of the **We Belong** survey of adults with Asperger's Disorder and high functioning autism. Findings from the parent survey and service provider interviews are available in separate reports.

The report is divided into thematically structured chapters as follows:

- » Chapter 1: Methodology
- » Chapter 2: Respondent profile
- » Chapter 3: ASD, health and wellbeing
- » Chapter 4: Education
- » Chapter 5: Employment
- » Chapter 6: Social life
- » Chapter 7: Independence and daily life
- » Chapter 8: Future aspirations
- » Chapter 9: Discussion of findings

Chapters 3 to 8 present 'headline' data pertaining to the chapter theme, as well as exploring how responses to particular questions on the survey may be meaningfully related to other responses. In addition, where appropriate, reported findings have been 'cross-tabbed' by key demographic variables, namely:

- » gender
- » age
- » location (urban or non-urban)
- » relationship status (whether or not respondent has a romantic partner)
- » non-school qualification status (whether or not respondent has attained a TAFE or university qualification)
- » employment status (whether or not respondent has a job).

*At various points of the report, comparisons are drawn between aspects of the We Belong study findings and related data from other sources; mostly the Australian Bureau of Statistics (ABS).*

At various points of the report, comparisons are drawn between aspects of the **We Belong** study findings and related data from other sources; mostly the Australian Bureau of Statistics (ABS). The aim of these comparisons is to highlight characteristics of the adult AD and HFA population that may broadly resemble, or differ from, the Australian population as a whole. However, in view of the complexities and nuances underlying the way in which terms are defined, data gathered, and statistics calculated across different research organisations and exercises, any such comparisons should be treated as indicative rather than exact or conclusive.



# Chapter 1: Methodology

This chapter provides an overview of the development, distribution and analysis of the survey for adults with AD and HFA that was employed in the **We Belong** study.

## Questionnaire development

The survey questionnaire was developed by the Aspect research team with the support of an advisory group, which included ASD specialists, educators, and representatives from the adult ASD and parent communities. The main topics covered in the questionnaire were health, education, work, family and social life, community involvement, and daily living.

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The questionnaire combined a mix of 'tick-box' and open question formats, aimed at generating a range of both quantitative and qualitative data in relation to each key topic.

After the advisory group had agreed an initial draft of the questionnaire, it was piloted with three members of an Aspect-run social group for adults with ASD. The pilot session took place during one of the regular social group meetings and was facilitated by a member of the research team. The three pilot group participants were asked to complete the draft questionnaire and provide comments and suggestions relating to factors such as topic content, question wording, visual presentation, clarity of instructions, and overall length.

The feedback from the pilot session was largely very positive, leading to only some minor revisions to question wording and instructions before a final version of the questionnaire was signed off by the advisory group.

## Target population

In order to be eligible for participation in the study, it was required that respondents:

- » be resident in Australia;
- » be aged 18 or over at the time of completing the survey;
- » have a diagnosis of Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder - Not Otherwise Specified (or be able to state that they believed they met the criteria for an ASD diagnosis, without having had this professionally confirmed); and
- » have no intellectual disability; that is, be 'high functioning'.

## Promotion and distribution

The survey was promoted through a number of channels, including:

- » the Aspect website, Facebook page and Twitter account;
- » Aspect service managers;
- » contacts and networks in the wider autism community;
- » targeted mailouts to service providers;
- » selected local, national and online social media outlets.

The feedback from the pilot session was largely very positive.

The questionnaire was made available in two formats:

- » as a paper document, mailed or distributed to participants for completion by hand and returned to Aspect in a reply-paid envelope;
- » as a 'fillable' PDF form, hosted by Adobe® Acrobat® X Pro and accessed via a hyperlink on the Aspect website, to be completed and submitted electronically.

## Response screening

Returned questionnaires were screened against the eligibility criteria noted above. This process resulted in seven questionnaires being excluded from the study: two because the respondents indicated that they lived outside Australia, and five because the respondents indicated that they were aged under 18.

## Data management and analysis

A survey database was created in the PASW Statistics software program, with responses either entered manually (from paper questionnaires) or imported electronically (from online questionnaires).

A mix of numerical, statistical and thematic analysis methods were applied to different aspects of the data. These are explained through the course of the report as relevant.

*Coding frameworks were drafted by individual members of the research team.*

In the case of some of the open-ended survey questions, coding frameworks were devised that allowed responses to be grouped into thematic categories, and in turn be subject to numerical and statistical analyses. Coding frameworks were drafted by individual members of the research team and reviewed by other members to ensure agreement on the conceptual grouping of responses. The data coding process itself was likewise undertaken by individual members of the research team, following which randomly selected portions of coding were checked and verified by a colleague. Any instances of disputed codes were discussed verbally until agreement was reached.

## Chapter 2: Respondent profile

This chapter provides a demographic overview of the We Belong adult survey respondents.

### Response total

A total of 313 valid questionnaires were received and included in the analysis. Of these, 171 were completed in paper format and 142 were completed online.

### Gender

Seventy-one per cent of respondents were male and 29 per cent were female.

The predominance of males in the sample is not unexpected, in view of the well-recognised gender imbalance in ASD diagnoses. However, it is notable that there is a higher proportion of females in the **We Belong** respondent group than might be expected in an average clinical population. The male-female diagnostic ratio for ASD is commonly considered to be around 4 to 1 (Whiteley et al., 2010), while the male-female ratio in this sample is approximately 2.3 to 1.

Whilst there is no immediately obvious explanation for the gender profile of the respondent group being shaped in this way, it may be considered a strength of the study that it has generated a strong subset of data pertaining to females with ASD, given the relative dearth of targeted research in this area (Gould & Ashton-Smith, 2011).

### Age

For the purposes of the survey analysis, respondents' ages were calculated (from self-reported date of birth) as at 1st January 2012.

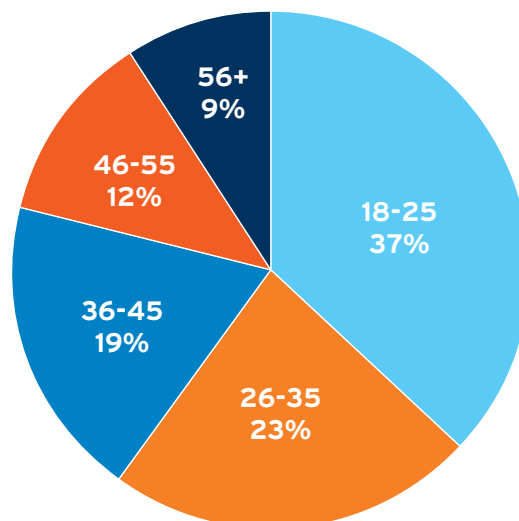
Respondents ranged in age from 18 to 70, with a median age of 30 years. **Figure 2.1** presents a breakdown of the respondent group by specified age brackets; namely 18 to 25 and ascending decades thereafter.

Like females, older people have historically been under-represented in autism research, and especially in work that engages directly with the ASD population. For example, Stuart-Hamilton et al. (2009), in a review of international literature on adults with AD and HFA, identified just five qualitative studies that included individuals over the age of 30 as participants. The **We Belong** dataset significantly addresses this gap in current knowledge by providing in-depth insights into the lives of 122 adults with AD and HFA in the 30-plus age group.

**Figure 2.1: Distribution of respondents by age group**

Respondents: n=301

Missing data: n=12



## Marital and family status

**Figure 2.2** provides a breakdown of the marital/relationship status of survey respondents. As noted in the chart, respondents who reported that they were separated or divorced (n=12) were classified as 'single' for the purposes of analysis. Respondents who indicated that they were in a romantic relationship were classed as 'dating' if they were not living with their partner and 'de facto' if they and their partner lived together.

The finding that 21 per cent of adults in the **We Belong** study sample were married or in a de facto relationship contrasts noticeably with the 2011 Australian Census data, which showed almost half (49 per cent) of Australian adults to be in a registered or de facto marriage.

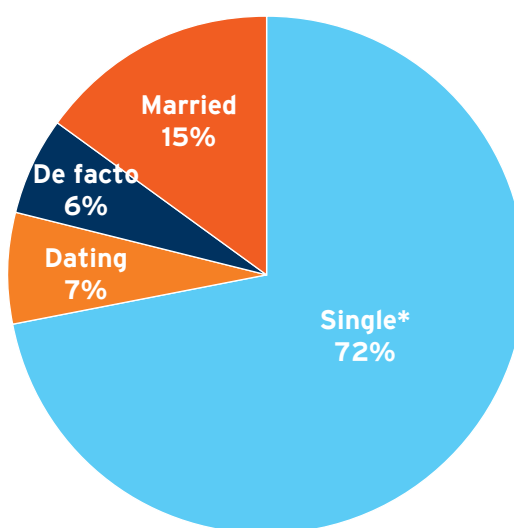
Eleven per cent of respondents indicated that they had at least one child aged 16 or under.

**Figure 2.2: Distribution of respondents by relationship status**

Respondents: n=309 (not shown: n=1 widowed)

Missing data: n=4

\*Includes separated/divorced



## Location

### State and territory

All eight Australian states and territories were represented in the survey sample, with the highest proportions of respondents found in New South Wales, Victoria and Queensland. **Table 2.1** presents a breakdown of the respondent group by current state or territory of residence, alongside the corresponding distribution of the Australian population as a whole.

**Table 2.1** indicates that the overall distribution of respondents across Australian states and territories is to some extent commensurate with national population statistics. However, there is an as-expected bias towards New South Wales (the 'home state' of Aspect) and a degree of under-representation in Western Australia and South Australia.

**Table 2.1: Distribution by state and territory of 'We Belong' respondents and Australian population**

	'We Belong' respondents (%)	Australian population (%)*
New South Wales	44	32
Victoria	26	25
Queensland	17	20
Australian Capital Territory	4	2
Tasmania	3	2
Western Australia	3	10
South Australia	2	7
Northern Territory	1	1

\*Source: ABS Cat. 3101.0 - Australian Demographic Statistics, Sep 2011

### Geographic region

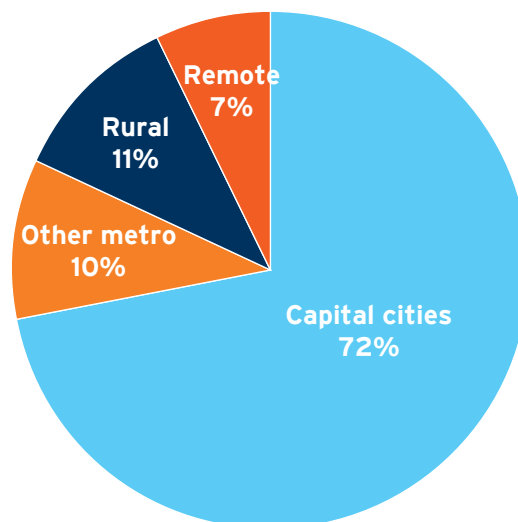
Figure 2.3 presents a breakdown of the respondent group by geographic region type. Respondents were assigned to regions according to their self-reported city or town of residence, using the Australian Government's Rural, Remote and Metropolitan Areas (RRMA) classification system.

Just under three-quarters (72 per cent) of respondents were classified as living in capital cities, with a further ten per cent living in other major metropolitan areas, such as Newcastle in New South Wales, Geelong in Victoria and Gold Coast in Queensland. Eleven per cent of respondents lived in large or small rural areas, and the remaining seven per cent in remote areas.

**Figure 2.3: Distribution of respondents by geographic region**

Respondents: n=303

Missing data: n=10



### Racial and ethnic background

Respondents were asked to indicate what racial or ethnic group they considered themselves to belong to. Figure 2.4 presents a breakdown of the respondent group according to these self-classifications of racial/ethnic background.

As would be expected, a sizeable majority (68 per cent) of respondents identified as being Australian, including n=1 respondent of Aboriginal or Torres Strait Islander origin. The second largest subgroup of respondents (18 per cent) consisted of those identifying as British or European. Eight per cent of respondents reported that they were of mixed racial/ethnic origin, and three per cent identified as Asian. For the purposes of analysis, the remaining three per cent of respondents were collectively classified as being of 'other' racial/ethnic origin. Within the survey sample, this subgroup included individuals of North American, Middle Eastern, Pacific Islander and other Oceanic background.

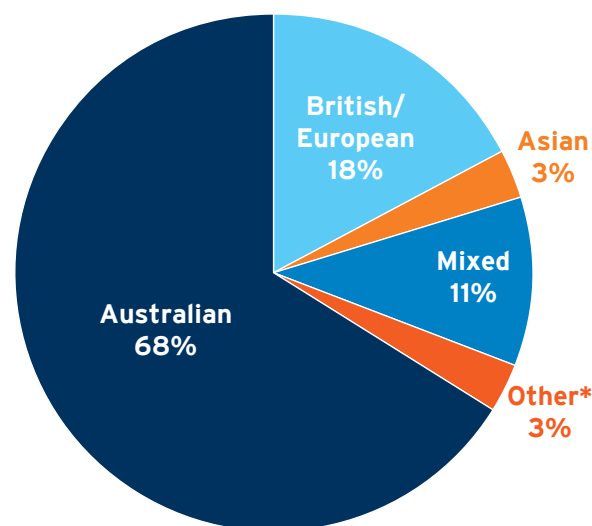
Ninety-five per cent of respondents reported speaking English as their first language.

**Figure 2.4: Distribution of respondents by racial/ethnic background**

Respondents: n=309

Missing data: n=4

\*North American, Middle Eastern, Pacific Islander and other Oceania



## Chapter 3: ASD, health and wellbeing

This chapter reviews those sections of the **We Belong** survey data pertaining to ASD diagnosis and to broader aspects of health and wellbeing.

### Diagnostic profile

**Figure 3.1** presents a breakdown of the respondent group by self-reported ASD diagnosis, according to the DSM-IV classification system (American Psychiatric Association, 1994).

Three-quarters (75 per cent) of respondents gave their diagnosis as Asperger's Disorder, 18 per cent as Autistic Disorder, and two per cent as PDD-NOS.

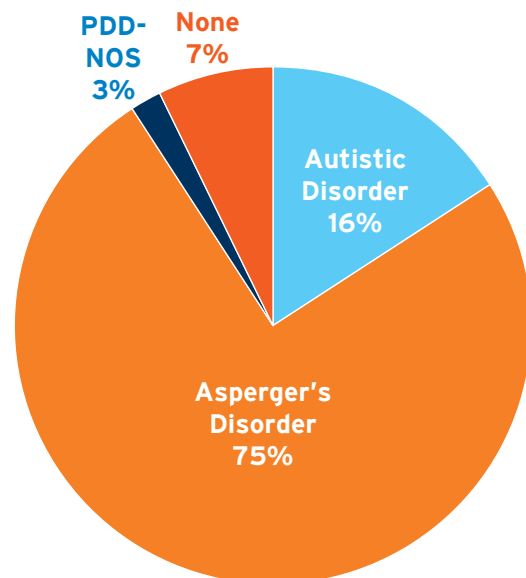
A further seven per cent of respondents (n=20) ticked the alternative response box to indicate they agreed with the statement: *"I believe I have an autism spectrum disorder, but I have not received a professional diagnosis"*. Key characteristics of this small subset of respondents are explored briefly at the end of this chapter

**Figure 3.1: Distribution of respondents by ASD diagnosis**

Respondents: n=306

Missing data: n=7

\*No professional diagnosis: ASD suspected or self-diagnosed



### Age of diagnosis

**Figure 3.2** presents a breakdown of the respondent group by the age at which an ASD diagnosis was received. The 20 respondents who stated that they had not received a professional ASD diagnosis were excluded from this analysis

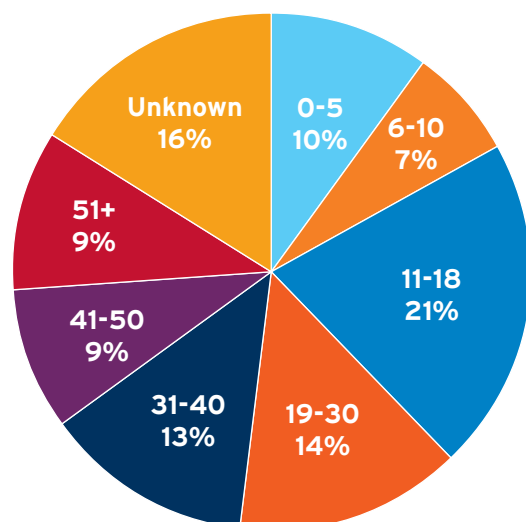
**Figure 3.2** indicates a wide spread in the ages at which respondents received an ASD diagnosis. Within the survey sample, the earliest reported diagnoses were received at age two and the latest at age 66. Just ten per cent of respondents were diagnosed during their pre-school years (up to the age of five), with close to half (45 per cent) diagnosed after the age of 18. The median age of diagnosis for all respondents was 23 years, with no difference between males and females.

Sixteen per cent of respondents indicated that they either did not know, or could not remember, at what age they received their diagnosis.

**Figure 3.2: Distribution of respondents by age of diagnosis**

Respondents: n=278

Missing data: n=4



Together, these studies and reviews have highlighted the vastness and complexity of adult autism as a research field.

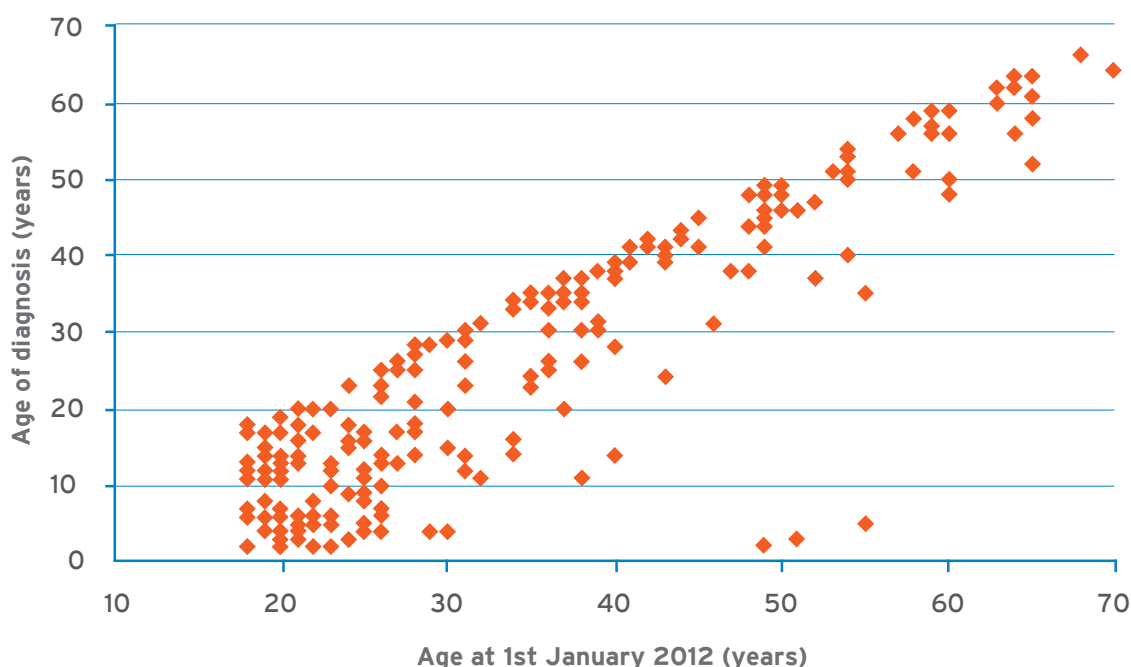
As noted in the Introduction, there has been a substantial increase in diagnosis rates for ASD since the earliest prevalence studies were conducted in the 1960s (Williams et al., 2008). This trend is variously attributed to a heightening awareness of the disorder amongst parents and professionals; the gradual broadening of the diagnostic criteria; the now more frequent identification of children with mental retardation or language impairment as also having autism; and a growth in early-age diagnosis (Bishop et al., 2008; Bishop et al., 2010; Weintraub, 2011). This being the case, we might expect to see an overall pattern of the older adults in this study having been diagnosed with ASD later in life than their younger co-respondents.

**Figure 3.3** confirms this anticipated relationship between chronological age and age of ASD diagnosis for the survey sample. The correlation shown in the graph is statistically significant. Respondents who did not know, or could not remember, the age at which they were diagnosed were excluded from this analysis.

In descriptive terms, **Figure 3.3** indicates a general trend for adults aged 30 and over at the time of the survey (that is, born up to 31st December 1981) to have been diagnosed with ASD within the last ten years of their life to date. Out of a total of 122 respondents in the 30-plus age group, there were only five recorded instances of a diagnosis being obtained before age ten, and a further nine before age 20. For respondents aged under 30 (born from 1st January 1982 onwards) age of diagnosis was more varied, with around half of the 113 individuals in this group having received their diagnosis between two and ten years of age.

**Figure 3.3: Age of diagnosis by chronological age**

Respondents: n=235



## Health and wellbeing issues

In a question designed to explore their health and wellbeing, respondents were presented with a list of nine aspects of physical and mental health and asked to select one of four possible response statements in relation to each, namely:

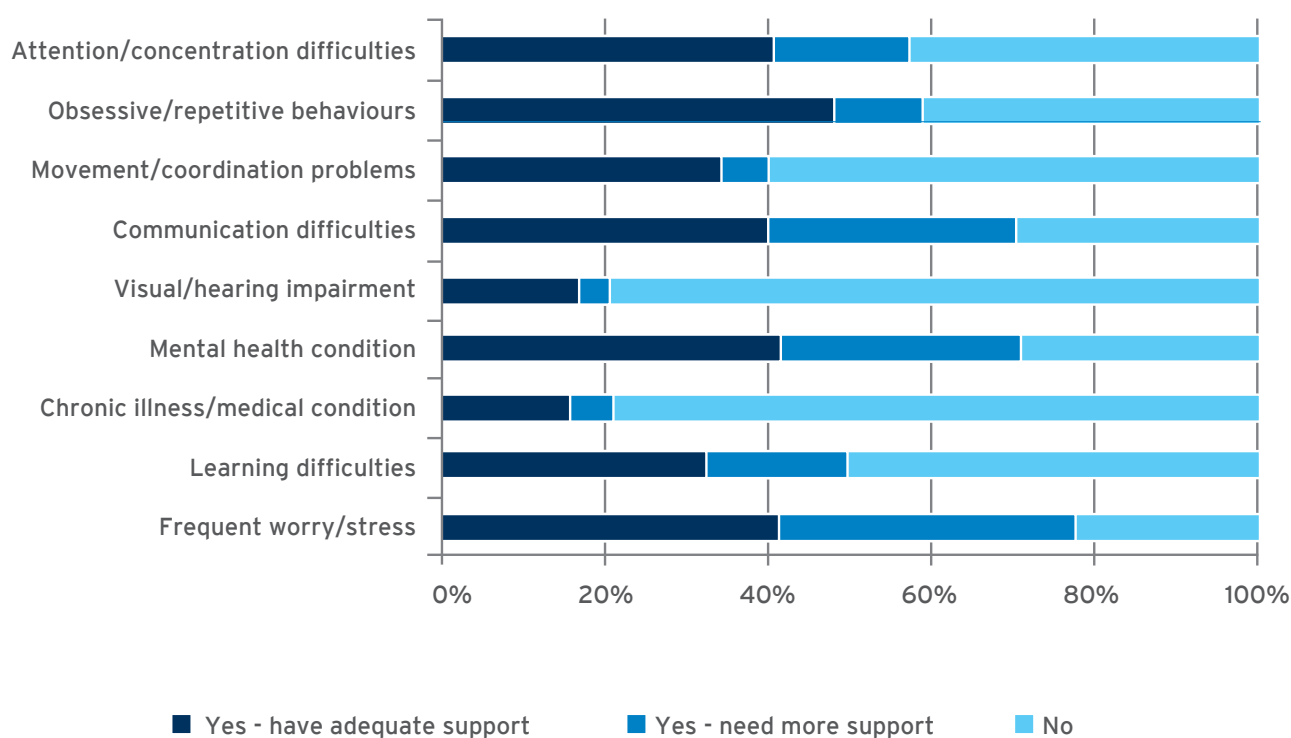
- » Yes - I have this condition, but I don't need any special support for it
- » Yes - I have this condition, but I am already getting enough support for it
- » Yes - I have this condition, and I need more support for it
- » No, I don't have this condition.

Figure 3.4 summarises the responses given to this question. For the purposes of analysis, the first two response options listed above were collapsed into a single category that denoted no outstanding support needs in the area shown.

From the graph, three health and wellbeing issues stand out for their relatively high prevalence within the adult ASD population, namely:

- » Frequent worry or stress, experienced by **78 per cent** of respondents.
- » Mental health conditions, experienced by **71 per cent** of respondents.
- » Communication difficulties, experienced by **71 per cent** of respondents.

Figure 3.4: Health and wellbeing issues





Further analysis revealed a small number of variations in these findings according to key demographic variables, as below:

- » Respondents living in rural areas were more likely to report experiencing frequent worry or stress (87 per cent) than those living in urban areas (76 per cent).
- » A higher proportion of females (83 per cent) than males (67 per cent) reported having a mental health condition.
- » Those reporting a mental health condition were on average older (mean age 35 years), than those reporting no mental health condition (mean age 31 years).

Various research papers have explored the comorbidity of ASD with mental health disorders, and links have been found to symptoms such as low self-esteem, depression, anxiety, coping deficits, and unstable temperament (Goode et al., 1994; Ghaziuddin et al., 1998; Soderstrom et al., 2002; Berney, 2004; Ozonoff et al., 2005). Moreover, it has been suggested that individuals at the 'high functioning' end of the autism spectrum may be at greater risk of poor mental health than those who have an intellectual disability as part of their ASD. Part of the reason for this may be that the former group are able to more clearly recognise and understand their own social and cognitive challenges, whilst feeling powerless to change; thus creating a distress and embarrassment that may not be experienced by those with lower intellectual ability.

*The high proportion of adults reporting communication difficulties is not unexpected, given that this deficit area forms one of the three core defining features of ASD.*

The high proportion of adults reporting communication difficulties is not unexpected, given that this deficit area forms one of the three core defining features of ASD. This finding highlights the subtleties of the challenges experienced by this population, who have followed a normal path of language development and are often highly articulate with impressive vocabularies, and yet struggle with the nuances and pragmatics of both expressive and receptive communication.

Aside from these three most prevalent health and wellbeing concerns, half or more of the respondent group identified as having obsessive or repetitive behaviours (59 per cent), problems with attention or concentration (58 per cent), and learning difficulties (50 per cent). In addition, 40 per cent indicated that they experienced problems with movement or coordination.

These are all issues that fit within the general profile of an autism diagnosis or that are otherwise common to those with ASD. Obsessive and repetitive behaviours are linked to deficits in social imagination and may also be a means of managing anxiety or moderating sensory input. Difficulties with attention, concentration and learning (in the absence of a global intellectual disability) are rooted in the cognitive processing deficits associated with autism, including poor executive functioning and weak central coherence (Costley et al., 2012). A high proportion of individuals with ASD display motor impairments such as poor coordination and balance, awkward gait or posture, slow reflexes and general clumsiness (Mosconi et al., 2011).

*These are all issues that fit within the general profile of an autism diagnosis or that are otherwise common to those with ASD.*

Around one in five (21 per cent) of the adults surveyed stated that they suffered from a long-term (chronic) illness or medical condition. Research has indicated that individuals with ASD may be at elevated risk of certain physical illnesses and conditions, including epilepsy and other seizure disorders, gastrointestinal dysfunction, sleep disorders, metabolic disorders, osteoporosis and obesity (Bauman, 2011).

Visual and/or hearing problems were also reported by 21 per cent of study participants. Whilst there is little, if any, research evidence expressly linking autism with vision impairment, a small number of studies have suggested that hearing loss and deafness are more common amongst individuals with ASD than in the general population (Rosenhall et al., 1999; Psillas & Daniilidis, 2003; Gayda & Saleh, 2004; Tas et al., 2007).

### Unmet support needs

As illustrated in Figure 3.4, there are substantial numbers of adults with AD and HFA who experience ongoing health and wellbeing needs and yet consider the support they are receiving (if any) to be inadequate. **Table 3.1** specifies, in descending order of magnitude, the proportions of respondents expressing 'unmet needs' for support in the nine health and wellbeing areas discussed above.

**Table 3.1** indicates that the three health and well-being issues most commonly experienced by the adult ASD population – frequent worry or stress, communication difficulties, and mental health conditions – are also the three for which external support seems least readily available, accessible or satisfactory. Over 40 per cent of respondents affected by each of these health and well-being issues indicated that they needed more support to help them manage it. In addition, close to or over one-third of adults who identified as having learning difficulties, a visual or hearing impairment, and problems with attention or concentration indicated a need for greater support.

Over 40 per cent of respondents affected by each of these health and wellbeing issues indicated that they needed more support to help them manage it.

Respondents were somewhat less likely to report unmet support needs for a chronic illness or medical condition, obsessive or repetitive behaviours, and problems with movement or coordination.

**Table 3.1: Percentages of respondents expressing unmet support needs for health and wellbeing issues**

	Respondents with unmet support needs (%)*
Frequent worry or stress	47
Communication difficulties	43
Mental health condition	42
Learning difficulties	35
Visual or hearing impairment	31
Problems with attention or concentration	29
Chronic illness or medical condition	21
Obsessive or repetitive behaviours	19
Problems with movement or coordination	18

\*Percentages are based on total numbers of respondents who reported experiencing each health and wellbeing issue

## Access to health services

Respondents were asked to indicate whether they were currently receiving, or would like to receive, support from a range of mental and allied health services. The response options to this question were as follows:

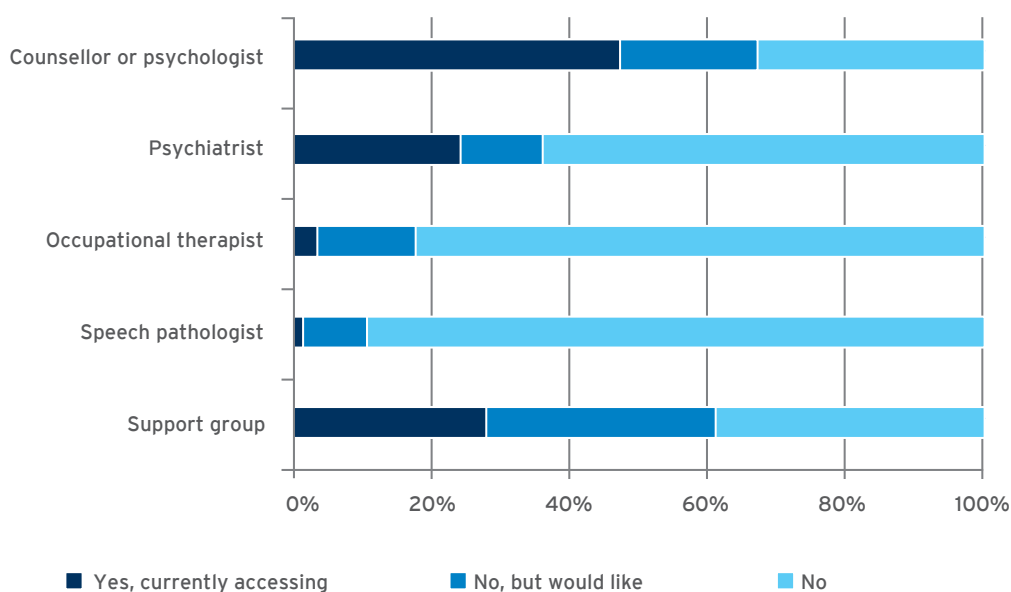
- » Yes, I am currently receiving this kind of support
- » No, but I would like to get this kind of support
- » No, I don't need this kind of support.

**Figure 3.5** summarises the responses to this question. It indicates that the two types of health service most in demand by adults with ASD (that is, those that received the highest numbers of responses: “Yes, I am currently receiving this kind of support” or “No, but I would like to get this kind of support”) are counselling and psychology services (67 per cent) and disability support groups (61 per cent).

The data further suggest that, of these ‘top two’ health service options, counselling and psychology services may be more readily available or accessible to the adult ASD population than support groups. Approximately two respondents were currently seeing a counsellor or psychologist for every one respondent who was not receiving such support even though they would like to. In contrast, respondents who (against their wishes) had no access to a support group marginally outnumbered those who were currently part of such a group.

A little over one-third (37 per cent) of participants expressed a need for the support of a psychiatrist, with just over one-third of this group not currently accessing any such support.

**Figure 3.5: Access to health services**



Further analysis confirmed that the use of and/or desire for counselling and psychology services, support groups and psychiatric intervention did not occur arbitrarily through the study population, but rather was directly related to the expression of mental health needs. It was the case for all three of these services that respondents who reported experiencing frequent worry or stress were significantly more likely to be accessing the service, or to identify the need for it, than those for whom worry or stress was not a concern.

The same pattern of findings emerged in relation to respondents who did and did not report having a mental health condition.

Smaller overall proportions of respondents indicated that they were accessing, or would like to access, occupational therapy (18 per cent) and speech pathology (11 per cent) services. In both cases, the majority of these respondents fell into the ‘unmet need’ category, in that they were not currently accessing this type of service even though they would like to.

## Respondents without a professional ASD diagnosis

For the most part, intellectually capable adults who come to believe that they meet the criteria for an autism spectrum disorder will be at liberty to decide for themselves whether or not to pursue a formal diagnosis. Public autism associations and service providers will often advocate the benefits to adults of having their suspected ASD professionally confirmed. Some of the positive outcomes associated with obtaining a diagnosis are considered to be:

- » enhanced self-understanding
- » improved knowledge of ASD more generally and the capacity to explain it to others
- » legitimised access to disability support services and funding
- » increased opportunities for involvement in the 'ASD community'.

Nevertheless, there may be many adults who choose not to 'formalise' their suspected or self-diagnosis of ASD. A recent epidemiological study in the UK (Brugha et al., 2011) provided initial evidence of a high level of undiagnosed autism within the adult British population, but did not expressly profile the characteristics of this 'hidden' group.

The 20 We Belong respondents who stated that they had not received a professional ASD diagnosis exhibited a slightly different demographic, educational and employment profile to the study population as a whole.

Collectively, the 20 We Belong respondents who stated that they had not received a professional ASD diagnosis exhibited a slightly different demographic, educational and employment profile to the study population as a whole (Table 3.2). They tended to be older; they were more likely to be married or in a de facto relationship, and more likely to have children aged 16 or under. They were also more likely to have completed Year 12 schooling or an equivalent educational qualification, and somewhat more likely to be currently employed.

From a health and wellbeing perspective, adults without a formal ASD diagnosis were less likely than their co-respondents to report experiencing frequent worry or stress, as well as less likely to report having a mental health condition.

**Table 3.2: Selective profile of respondents without a professional ASD diagnosis versus whole study population**

	Undiagnosed (n=20)	All (n=313)
Median age (years)	44	30
Married or de facto (%)	55	25
Have children under 16 (%)	35	11
Completed Year 12 (%)	85	67
Currently employed (%)*	65	54
Experience frequent worry or stress (%)	55	78
Have mental health condition (%)	53	71

\*Excludes respondents currently in full-time education

Given the relatively small number of respondents in the 'undiagnosed' group, evidently caution must be exercised in interpreting or extrapolating these comparative data. However, there is some suggestion that adults may be less inclined to seek a diagnosis for a suspected ASD if they are in a stable relationship, have a family, are educationally well qualified and have a job. As a generalisation, it might be that these objectively 'favourable' life circumstances to some extent offset the kind of incentives to obtaining a diagnosis described above, especially those related to social inclusion and financial support. The same may not be true for those in more isolating or disadvantaged circumstances, such as being single or unemployed.

Adults may be less inclined to seek a diagnosis for a suspected ASD if they are in a stable relationship, have a family, are educationally well qualified and have a job.

The tentative indication that 'undiagnosed' adults with ASD are, comparatively speaking, less predisposed to ongoing mental health issues could be interpreted in a number of ways. One possibility is that, in line with the hypothesis above, individuals who are in good mental and emotional health may foresee fewer benefits to obtaining the additional information and support that would accompany a formal diagnosis. From another point of view, it may be the case that adults who do have mental health concerns are 'by default' more likely to have an as-yet undetected ASD picked up by a professional, purely by virtue of their closer contact and involvement with health services.

In order to explore these issues further, respondents who stated that they had not received a professional ASD diagnosis were asked to write a brief explanation of why this was the case. Nineteen of the 20 respondents in this group provided answers to this question, which are summarised thematically below.

**Theme 1.** Nine respondents indicated that they **did not consider it necessary or beneficial** to obtain a formal diagnosis. In some cases, respondents were **confident and content to 'self-diagnose'**. Responses classified in this category included:

*"Can't see strong benefit in a diagnosis - other than perhaps out of interest, or saving money in attending Asperger's Syndrome meetings."*

*"I'm intelligent and can work out coping strategies myself."*

*"Have read enough to self-diagnose."*

**Theme 2.** Six respondents indicated that whilst they had sought or were interested in obtaining a diagnosis, confirmation of this was currently **pending or uncertain**. For example:

*"I have had several 'checklists' done that say I have nine out of ten identifiers, but no one will give me a definite diagnosis. I'm not sure that I do fit all the categories."*

*"My sociologist said I do [have an ASD], and so did other people who are sociologists, but I'm high functioning. They said I'm borderline and they're more concerned [about] how I might take it."*

*"Currently awaiting an appointment (last three aborted due to ill health or work conflicts)."*

**Theme 3.** Two respondents indicated that they had encountered specific **service barriers** that had prevented them from obtaining a diagnosis, namely:

*"I have not received a diagnosis because I had to do the research...all the professionals think I have brain damage."*

*"It is too expensive to get a professional diagnosis."*

**Theme 4.** Two respondents identified their **parents** as being primarily responsible for their lack of a formal ASD diagnosis. It is arguable that in making these statements, the individuals concerned have implied that they do not intend to now seek a diagnosis as an adult.

*"Parents were not aware of reason for degree of life challenges."*

*"As a young child growing up, my parents were too busy to deal with such issues."*

In summary, among the small number of undiagnosed adults in the study, there was an approximately even divide between those who had no desire to obtain a formal diagnosis (Theme 1) and those who had been hindered from doing so by personal circumstances, service-related obstacles, or a general lack of clarity as to the nature of their 'disorder' (Themes 2 and 3). Theme 4 remains somewhat too ambiguous to classify in either direction.

## Chapter 4: Education

This chapter presents information on the educational attainments and experiences of adults with Asperger's Disorder and high functioning autism, as recorded in the We Belong survey.

### Current education

Just under one-third (31 per cent) of respondents indicated that they were currently enrolled in a course of study: 14 per cent on a full-time basis and 18 per cent on a part-time basis. The remaining 69 per cent of respondents were not undertaking any formal education at the time of the survey.

### Education settings attended

Figure 4.1 indicates the types of education setting attended by respondents at primary, secondary and tertiary level (including current enrolments). It should be noted that the percentages displayed in each subsection of the graph are not mutually exclusive and do not sum to 100, as respondents may have attended more than one

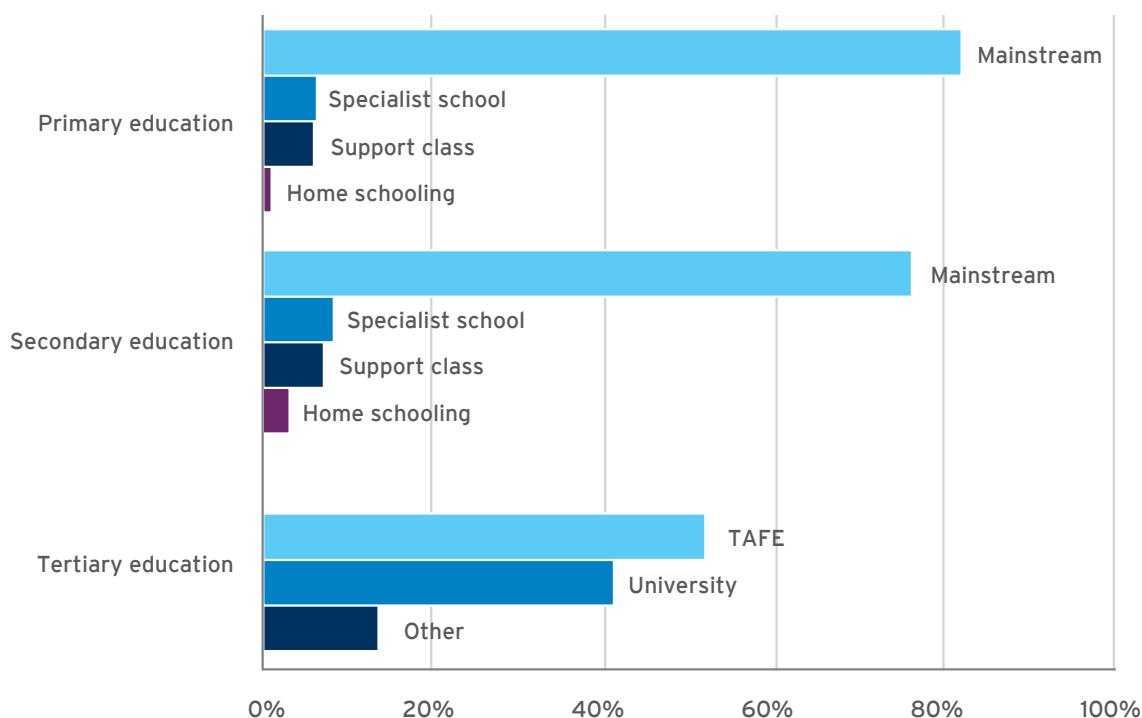
type of institution at different stages of their primary, secondary and/or tertiary education.

Figure 4.1 indicates that the majority of adults in the study attended mainstream schools for both their primary (82 per cent) and secondary (76 per cent) education. Relatively few respondents attended a support class as part of that mainstream education: six per cent at primary level and seven per cent at secondary level. Similarly, only small proportions of respondents (six and eight per cent respectively) were educated at specialist primary and secondary schools.

A very small minority (one per cent) of respondents were schooled at home during their primary years, with marginally more (three per cent) home schooled at secondary level.

At the time of the survey, 81 per cent of respondents had commenced or completed a course of study at a TAFE institute, university, or other accredited tertiary education provider.

Figure 4.1: Education settings attended





## Educational attainment

### Non-school qualifications

Non-school qualification attainment is used by the ABS as a gauge of the knowledge and skills required for professional, technical and vocational work. The term is applied to any qualification awarded outside formal primary and secondary education, including TAFE Certificates and Diplomas, and university degrees at undergraduate and postgraduate level.

The proportion of We Belong participants holding a non-school qualification is notably higher than this national aggregate, at 78 per cent.

The ABS reports that in 2011, 57 per cent of Australians aged 15 to 64 held a non-school qualification. The proportion of We Belong participants holding a non-school qualification is notably higher than this national aggregate, at 78 per cent. This may be reflective of the fact that the high functioning adult ASD population is, by definition, at the 'upper end of the curve' with regard to general intellectual ability.

### Highest qualification level

Another way to represent educational attainment within the study sample is to categorise respondents according to the highest level qualification they had completed at the time of the survey. This information is presented in Figure 4.2. The three categories shown encompass the following level-equivalent qualifications:

- » **Year 10:** School Certificate; TAFE Certificate I; TAFE Certificate II.
- » **Year 12:** Higher School Certificate (HSC); TAFE Certificate III; TAFE Certificate IV; Diploma; Advanced Diploma.
- » **Degree or higher:** Bachelor degree; Master's degree; Doctoral degree.

As indicated in the chart, at the time of the survey 13 per cent of respondents held a Bachelor or higher degree, while two-thirds (67 per cent) had gained their highest qualification at Year 12 level or equivalent. One in five (20 per cent) halted their formal education after Year 10.

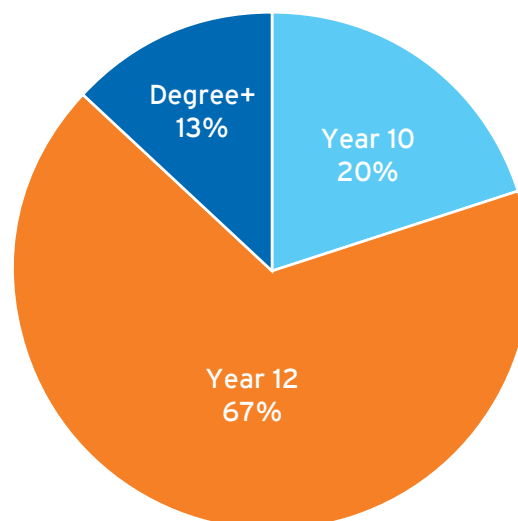
Despite the indication, as noted above, that adults with AD and HFA have higher overall rates of non-school qualification attainment than the population at large, the proportion of this group holding a university degree (13 per cent) is considerably below that reported by the ABS for all Australians in 2011 (25 per cent).

It should be borne in mind that these findings, together with those above, represent a time-limited 'snapshot' as opposed to a static picture of the educational attainments of the population being studied. As noted previously, 30 per cent of respondents were enrolled in ongoing education at the time of the survey, and there may be many more who will undertake further study during the course of their adult lives. Were the same population to be re-surveyed in years to come, it is possible that the qualifications profile would have substantially altered.

**Figure 4.2: Distribution of respondents by highest qualification level**

Respondents: *n*=283

Missing data: *n*=30



Despite the indication, as noted above, that adults with AD and HFA have higher overall rates of non-school qualification attainment than the population at large, the proportion of this group holding a university degree (13 per cent) is considerably below that reported by the ABS for all Australians in 2011 (25 per cent).

Were the same population to be re-surveyed in years to come, it is possible that the qualifications profile would have substantially altered.

It should be borne in mind that these findings, together with those above, represent a time-limited 'snapshot' as opposed to a static picture of the educational attainments of the population being studied. As noted previously, 30 per cent of respondents were enrolled in ongoing education at the time of the survey, and there may be many more who will undertake further study during the course of their adult lives. Were the same population to be re-surveyed in years to come, it is possible that the qualifications profile would have substantially altered.

### Halted qualifications

Just under one-quarter (23 per cent) of respondents reported that they had 'halted' at least one of the educational qualifications listed above; that is, had commenced studying or working towards it but abandoned it before completion. The most common halted qualification was the HSC, accounting for 37 per cent of abandoned courses.

The most common halted qualification was the HSC, accounting for 37 per cent of abandoned courses.

When asked to explain briefly why they had halted a course of study, respondents most frequently alluded to mental health issues and unmet learning support needs as having prevented them from following an intended qualification through to completion. Just under half of the total number of explanations provided in this section fell into one or other of these categories. Some of the specific issues mentioned here included:

- » stress
- » fatigue
- » depression
- » social anxiety
- » panic attacks
- » sensory overload
- » inability to focus
- » inability to 'keep up'.

### Support received during education

Learning, social and behaviour support represent three key mechanisms by which children (and adults) with ASD can be supported to overcome the challenges they face in the school environment and other education settings.

**Learning support** assists the student to understand lesson content, complete classwork and assignments in a satisfactory manner, and manage the planning and organisation demands of an academic workload.

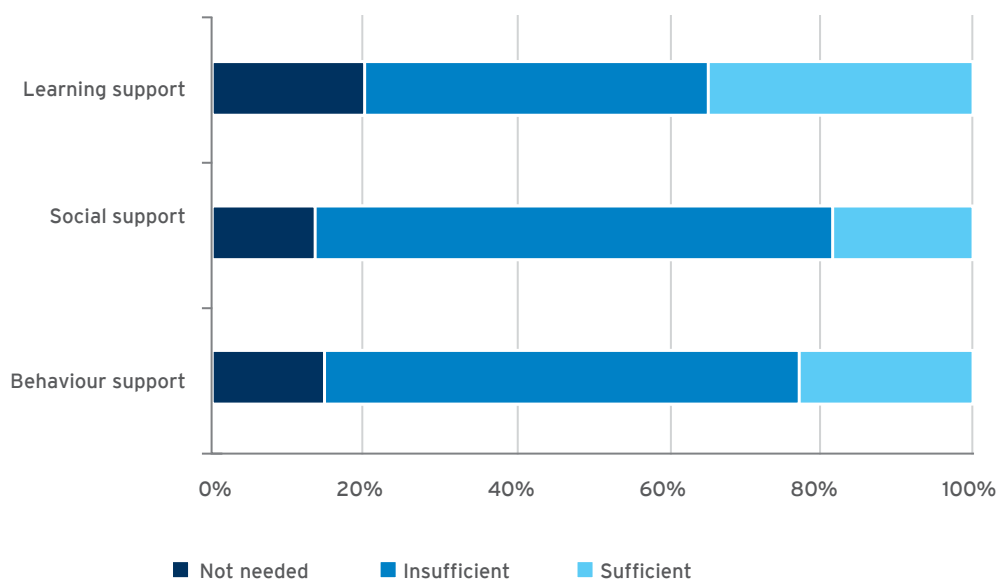
**Social support** encourages the student towards healthy relationships with peers through increased self-awareness, development of interpersonal and conversation skills, and strategies to address the anxiety generated by social situations.

**Behaviour support** is concerned with helping students to recognise, express and regulate their emotions, and to develop problem-solving abilities that reduce the likelihood of inappropriate behavioural responses to challenging situations.

Respondents were asked to give a retrospective assessment of whether or not they had received adequate learning, social and behaviour support during their time in education. They also had the option of stating that they had not required any additional support in these areas. Responses to this question are shown in Figure 4.3.



**Figure 4.3: Support received during education**



The data clearly indicate high levels of both perceived need, and unmet support for those needs, for the adults in the study during their time in education. Large majorities of respondents identified as having had additional needs in each of the three support areas of learning (78 per cent), social (84 per cent) and behaviour (83 per cent). However, in each case only a minority felt that the support they had received was adequate. Discounting those who stated that they did not require any special support in the areas shown, 58 per cent of respondents retrospectively reported insufficient learning support, 78 per cent insufficient social support,

and 73 per cent insufficient behaviour support.

Whilst experiences relating to social support in education were relatively consistent across the study population as a whole, there were some variations in experiences of learning and behaviour support according to both the age and geographic location of respondents (Table 4.1). Specifically, older adults and those living in non-urban locations appear to have faced greater disadvantages with regard to support provision.

**Table 4.1: Adequacy of learning and behaviour support in education by geographic location and age**

	Learning support		Behaviour support	
	Adequate	Inadequate	Adequate	Inadequate
Urban	46%	54%	31%	69%
Non-urban*	25%	75%	16%	84%
Mean age**	27 years	36 years	26 years	36 years

\*Urban/non-urban comparison is significant for learning support (Pearson Chi-square:  $\chi^2=6.231$ ,  $p<0.05$ ) and behaviour support (Pearson Chi-square:  $\chi^2=4.147$ ,  $p<0.05$ )

\*\*Age comparison is significant for learning support (one-way ANOVA:  $F=1.808$ ,  $p<0.01$ ) and behaviour support (one-way ANOVA:  $F=1.648$ ,  $p<0.05$ )

## 'Best and worst'

In order to generate a large body of qualitative insights into the educational experiences of adults with ASD, respondents to the We Belong survey were asked to briefly describe the 'three best' and 'three worst' things about their time in education. These responses were pooled, categorised and coded in line with the process outlined in Chapter 1. The outcomes of this analysis are summarised below.

### Best aspects of education

A total of 748 positive comments relating to education were recorded in the survey. These were categorised into seven key themes.

The 'top three' response themes relating to positive experiences in education were as follows:

**1. Learning and studying: 36 per cent of comments.** This category of responses included references to enjoying particular subjects; having the opportunity to pursue personal interests in an educational context; and a general sense of being challenged or enriched by the process of studying.

**2. Friendships and socialising: 15 per cent of comments.** Responses in this category generally referred to friendships formed in educational settings, or to other positive experiences of social contact, such as meeting people with similar interests or experiencing a sense of community.

**3. Teachers and support systems: 14 per cent of comments.** Responses were coded to this category if they spoke of positive memories of particular teachers, relationships with teachers and other educational staff, or support received whilst at school, college or university.

A total of 748 positive comments relating to education were recorded in the survey.

The remaining responses were classified under the following themes:

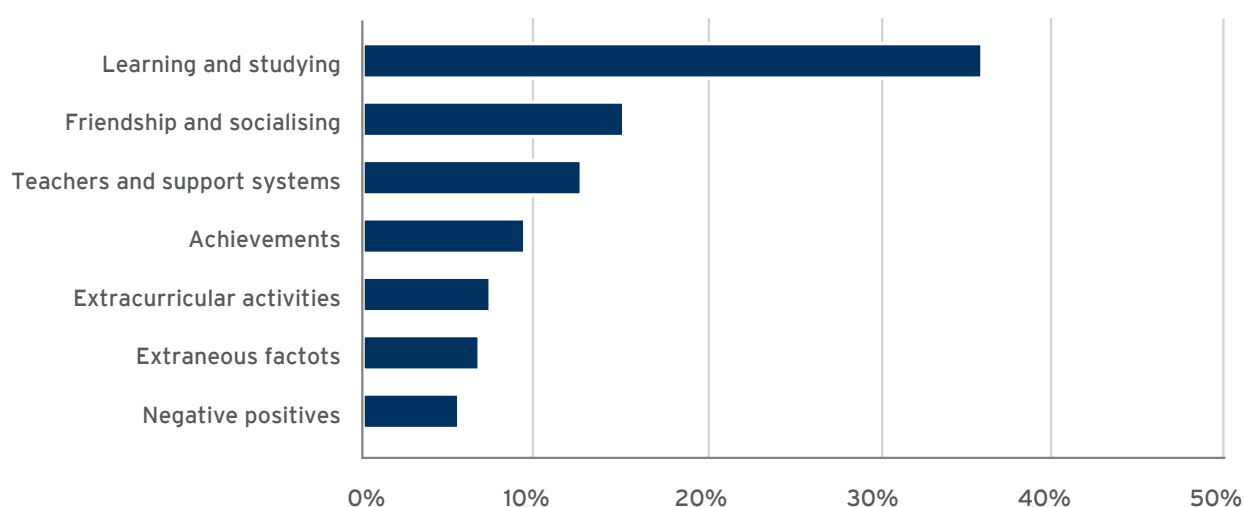
- » **Achievements (10 per cent):** positive memories or experiences related to attaining qualifications, as well as other formal or informal modes of achievement and recognition.
- » **Extracurricular activities (7 per cent):** positive memories or experiences related to sports, after-school clubs, school excursions etc.
- » **Extraneous factors (7 per cent):** positive memories or experiences relating only indirectly to the process of education, such as enjoying the journey to school or benefiting from student discounts.
- » **Negative positives (6 per cent):** comments that, whilst framed as 'positives', were in fact suggestive of negative experiences of education. Examples include:

*"Lunch - the freedom of being away from abusive teachers."*

*"The day I left school for ever and ever and went to uni where they treat you like a human being not a freak."*

**Figure 4.4** summarises the proportions of total positive comments about education falling into each of these categories.

**Figure 4.4: 'Best' aspects of education**



A residual six per cent of responses were categorised as **other/unclassifiable**. These were cases where the respondent recorded a statement that bore no relation to any of the foregoing themes, did not make logical sense, or was too vague to classify.

### Worst aspects of education

A total of 804 negative comments relating to education were recorded in the survey, and were categorised into five key themes.

A total of 804 negative comments relating to education were recorded in the survey.

The 'top three' response themes relating to negative experiences in education were as follows:

**1. Social experiences: 42 per cent of comments.** Responses in this category generally referred to experiences of being teased, bullied or socially excluded; having few or no friends; and feeling lonely, isolated or 'out of place'.

**2. Learning and studying: 29 per cent of comments.** Responses coded to this category tended to reflect struggles with the content, structure and demands of formal learning, often related to the individual's ASD characteristics. These might include:

- » specific learning difficulties or learning support needs, particularly around comprehension;

- » challenges related to motivation, self-organisation and time management;
- » stress, anxiety or depression attributed to the demands of learning and studying, particularly in relation to assignments and exams;
- » a general dislike of particular subjects or teaching methods.

**3. Teachers and school systems: 19 per cent of comments.** Responses were coded to this category if they spoke of negative memories of teachers and other educational staff; or of perceived failures by educational institutions or systems to understand and meet the respondent's support needs, particularly for ASD-related issues.

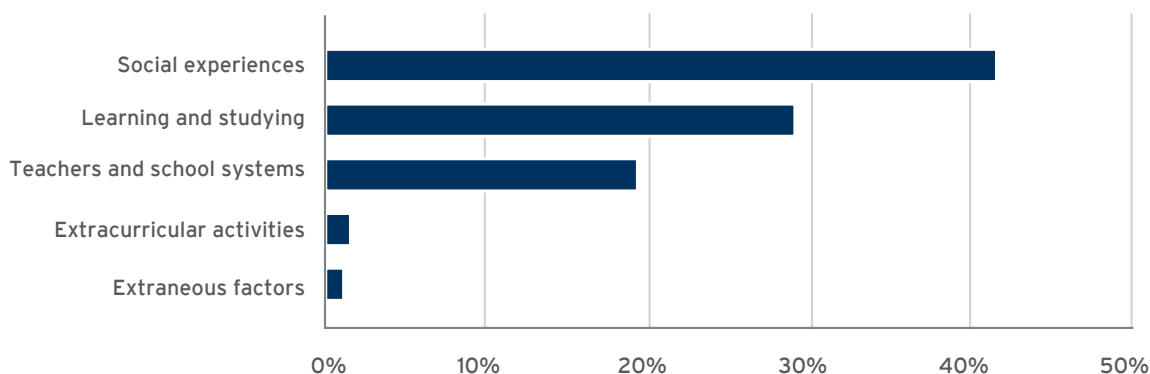
The remaining responses were classified under the following themes:

- » **Extracurricular activities (2 per cent):** negative memories or experiences related to sports, school excursions etc.
- » **Extraneous factors (2 per cent):** negative memories or experiences relating only indirectly to the process of education, for example:  
*"Uniforms - too hot, too cold, uncomfortable etc."*  
*"Commuting in the pouring rain."*

**Figure 4.5** summarises the proportions of total negative comments about education falling into each of these categories.

A further six per cent of responses were categorised as **other/unclassifiable** as per the definition given in the previous section.

**Figure 4.5: 'Worst' aspects of education**



## Bullying

The topic of bullying in education settings warrants particular discussion in this report because of its strong prevalence for the ASD population. As noted above, self-reported experiences of social isolation, exclusion and victimisation together comprised the most common 'worst thing' recalled by survey respondents about their time in education. A separate analysis showed that 72 per cent, or nearly three-quarters, of all adults in the study recorded at least one comment in this section relating to negative social experiences at school, college or university, many of which referred directly to bullying.

The topic of bullying in education settings warrants particular discussion in this report because of its strong prevalence for the ASD population.

A recent survey by the US-based Interactive Autism Network (IAN) explored in some depth the bullying experiences of over 1,000 children aged six to 15 with ASD, as part of which comparisons were drawn with the experiences of their typically developing siblings. Thirty-nine per cent of children with ASD were reported by their parents to have been bullied within the preceding month, in contrast to 12 per cent of unaffected siblings. Overall, 63 per cent of children with ASD had been bullied at some time in their lives. Common modes of bullying included teasing and mockery, name-calling, being ignored or excluded from social activities, and – to a lesser degree – physical intimidation or violence. Instances were also recorded of bully victims seemingly being deliberately provoked to aggression or a meltdown by their attackers.

Two 'historical' factors that emerged as significantly related to the experience of bullying were the adequacy of social support and the adequacy of behaviour support received while in education.

These findings are closely reflective of the bullying experiences reported by **We Belong** participants, from whom some illustrative quotes (in part-response to the question: "Please briefly describe the worst three things about your time in education") appear below.

*"Being singled out as a suitable target for constant harassment and ridicule."* **Female, 35**

*"Being bullied at school because I behaved differently to others in the class and was shy and weak."* **Female, 28**

*"Being voted the weirdest person at school."* **Male, 28**

*"Being marginalised and ignored."* **Female, 64**

*"Regular beatings and tearing of clothes by other students."* **Male, 55**

*"Retaliating/reacting to bullying violence."* **Male, 30**

In the context of this study, it is particularly interesting to note that the IAN survey found children with Asperger's Disorder to be at substantially greater risk of bullying than those with Autistic Disorder. If this diagnostic distinction can be treated as a crude proxy for high functioning versus non-high functioning ASD, then a possible explanation for this finding is that 'bullies' may be less inclined to victimise peers who show obvious signs of a disability; perhaps because – even to those with less sensitive consciences – this seems somehow intuitively more unacceptable. On the other hand, young people of normal intelligence who merely present as a little socially awkward or 'odd' may, in the words of the IAN authors, make "perfect targets". It would appear that this analysis rings true for large numbers of **We Belong** participants.

Within the **We Belong** study sample, the incidence of bullying (together with other negative social experiences) was consistent between genders and across age groups. However, two 'historical' factors that emerged as significantly related to the experience of bullying were the adequacy of social support and the adequacy of behaviour support received while in education. In both cases, approximately 80 per cent of respondents who stated that they had **not** received adequate support also spoke of having been bullied, in contrast to around 60 per cent of those who felt their social and behaviour support needs had been met.

There are a number of ways in which this finding could be interpreted, but one possible implication is that education-based interventions designed to foster social skills and behavioural regulation play a role in equipping young people with high functioning ASD to better ‘fit in’ with their neurotypical peers, thus lessening the risk of their being singled out by bullies. However, with bullying rates still standing at around 60 per cent for respondents who considered themselves to have received adequate social and behaviour support, clearly such interventions form at

most only a small part of the strategies required to address bullying within the ASD student population.

Further analysis showed that respondents who cited bullying as a ‘worst thing’ about their time in education were more likely than their fellow respondents to express a range of ongoing support needs in adult life. These comparisons are shown in Table 4.2. (See Chapter 7 for a more detailed analysis and discussion of these support needs within the study population as a whole.)

**Table 4.2: Comparison of support needs by reported experiences of bullying (per cent)\***

		Bullying reported	Bullying not reported
Support needed for...	improving social skills	66	46
	accessing leisure and social activities	46	27
	dating and relationships	57	36
	dealing with bullying or discrimination	53	30

*\*Comparisons of self-reported support needs between ‘bullied’ and ‘non bullied’ respondents were conducted using Pearson Chi-square tests and are significant for improving social skills ( $\chi^2=9.607$ ,  $p<0.01$ ), accessing leisure and social activities ( $\chi^2=9.717$ ,  $p<0.01$ ), dating and relationships ( $\chi^2=10.730$ ,  $p<0.01$ ) and dealing with bullying or discrimination ( $\chi^2=13.395$ ,  $p<0.01$ )*

In their original context within the questionnaire, the four support needs shown in Table 4.2 were presented as part of a list of 18 ‘independence and everyday life’ domains, with respondents asked to indicate the level of support they felt they required in each area. All 18 items were analysed for their statistical relationship to self-reported bullying experiences: only those indicated in Table 4.2 showed a significant association.

It is notable that all four of these support areas are concerned in some way with interpersonal and social interaction. (The remaining 14 related broadly to aspects of personal independence, community access, and social citizenship.) On these grounds, it might be hypothesised that individuals with high functioning ASD who face exclusion and victimisation during their education years are consequently debilitated in their confidence or capacity to navigate social interactions in adult life.

Another possible interpretation is that the same social difficulties or behavioural traits that in past times made individuals a particular target for bullies continue to present challenges for their social and interpersonal relating today, and are not ‘effects’ of the bullying per se. If this is the case, it highlights the concerning issue that the individual’s social support needs may have been ignored, unrecognised, or that any interventions received have not been highly successful.

Perhaps related to these findings, a separate analysis showed that respondents who cited bullying as a ‘worst thing’ about their time in education were twice as likely to say that they were currently dissatisfied with their social life (26 per cent) than those for whom bullying had **not** constituted a ‘worst thing’ (13 per cent). (See Chapter 6 for a more detailed analysis and discussion of this topic.)

A final point to highlight here is that participants' negative social experiences in education settings were not confined solely to ill-treatment at the hands of their peers. Rather, in a number of instances, teachers and other school staff were specifically implicated as the perpetrators of bullying. Cases were also reported of teachers seemingly being complicit in, or at least indifferent to, the bullying behaviour of other students against the individual with ASD.

*In a number of instances, teachers and other school staff were specifically implicated as the perpetrators of bullying.*

A 'step down' from deliberate teacher bullying, but not completely divorced from the concept, is the issue of educational staff misunderstanding, failing to adequately support, or unfairly treating students with ASD. Statements to this effect were captured under the 'teachers and support systems' response theme in relation to the 'worst three things about education' question.

Over one-third (35 per cent) of respondents recorded at least one comment that was classified to this theme, with some illustrative examples shown below.

*"Very clear signs that I needed significant support throughout education, but getting none because my marks were very good."* **Female, 30**

*"Telling teachers that I had some kind of learning problem and having them laugh at me."* **Female, 60**

*"Lack of clarity in direction and instruction concerning additional support on top of mainstream classes."* **Male, 31**

*"The support teachers I had did not understand how my support was detrimental to my social image."* **Male, 25**

*"Teachers trying to get me to answer a question or pointing out that I wasn't paying attention."* **Female, 26**

Interestingly, the incidence of negative comments classified under the 'teachers and support systems' theme was consistent across age groups. This suggests that, despite the general growth in public understanding and awareness of autism in recent years, there is still much ground to be covered with regard to informing and equipping professional educators to work effectively with students who have high functioning ASD.

## Chapter 5: Employment

This chapter presents information on the past and present labour market and employment experiences of adults with Asperger's Disorder and high functioning autism, as recorded in the We Belong survey.

### Current employment

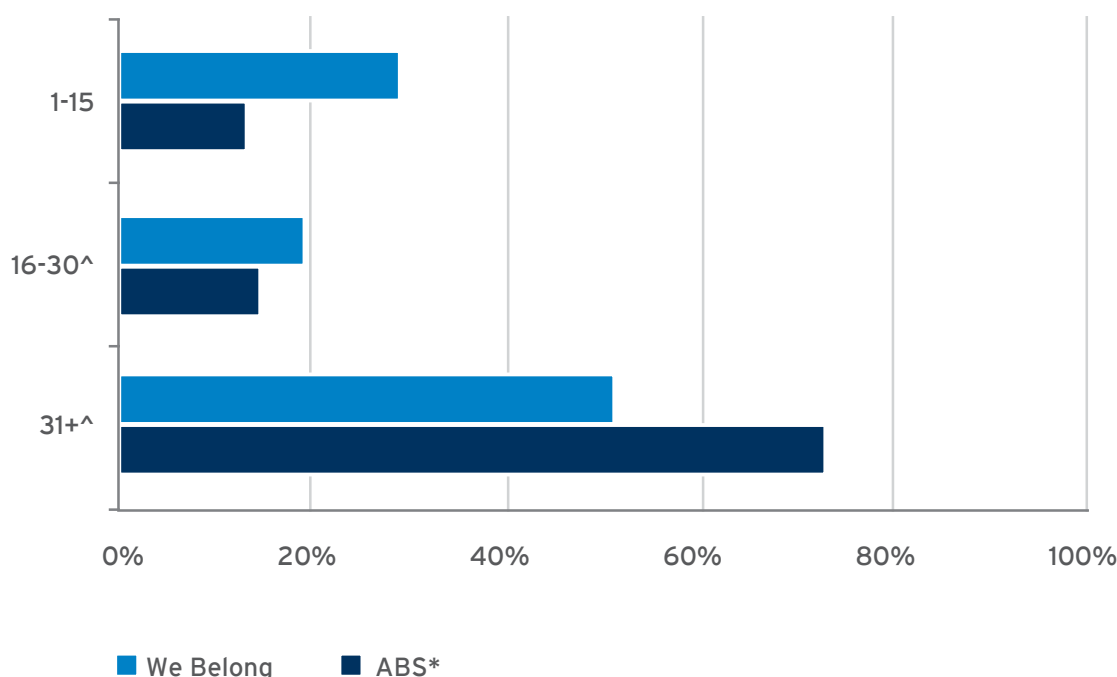
The following analyses exclude those respondents who indicated that they were enrolled in full-time education at the time of completing the survey (n=46). Whilst it is acknowledged that some individuals may combine full-time study with work (as was the case for n=4 of our survey participants), in labour market analysis terms these individuals can legitimately be deemed 'not available for work'.

Of the 267 respondents not in full-time education, just over half (54 per cent, n=143) reported having a paid job at the time of completing the survey. This figure contrasts markedly with the Australian national employment rate, which in June 2012 stood at 95 per cent.

### Hours of work

Figure 5.1 presents data on the number of hours normally worked per week by employed adults in the study, and provides a broad comparison with 2010 ABS data pertaining to the Australian workforce as a whole.

**Figure 5.1: Hours normally worked per week: We Belong and 2010 Australian workforce**



We Belong respondents: n=142; missing data: n=1

\*Source: ABS Cat. 6105.0 - Australian Labour Market Statistics, Oct 2010

^ABS working hour divisions are 16-29 and 30+



At the time of the **We Belong** survey, approximately half (51 per cent) of employed respondents were working more than 30 hours per week; one in five (20 per cent) were working between 16 and 30 hours, and the remaining 29 per cent were working 15 hours or less. It is apparent from Figure 5.1 that adults with AD and HFA tend to work reduced hours relative to the population as a whole. In particular, it is noted that the proportion of **We Belong** respondents working 15 hours or less per week (29 per cent) is more than double the corresponding figure for the overall Australian workforce (12 per cent).

### Type of job contract

**Figure 5.2** categorises employed respondents according to the type of job contract they were working under at the time of the survey. In order to permit comparison with ABS data, Figure 5.2 excludes self-employed persons, who made up 11 per cent of the total employment group.

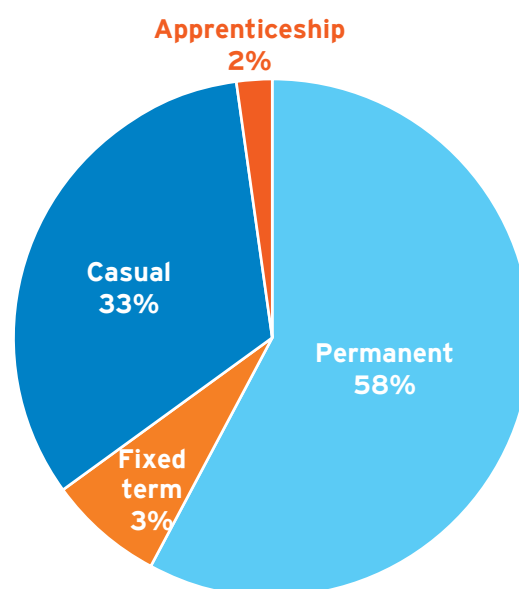
When benchmarked against national statistics, the data in **Figure 5.2** appear to indicate an overrepresentation of casual employment within the adult AD and HFA population. One-third (33 per cent) of employed respondents were working on a casual basis at the time of the survey; in contrast, just 21 per cent of the Australian labour force as a whole is made up of casual workers.

Conversely, the proportion of permanent and fixed-term employees in the study population (65 per cent) is notably lower than the corresponding national figure of 79 per cent.

**Figure 5.2: Distribution of respondents by type of job contract**

Respondents: n=125

Missing data: n=3



### Jobseeker and workplace support

Forty per cent of the employed adults in the study indicated that they had received some kind of assistance or support to get their current job. Within this group, 31 per cent of respondents had been supported by Disability Employment Services, and 31 per cent through Transition to Work programs. Twenty-two per cent had received informal support from their family or friends, while 20 per cent had been assisted by Centrelink.

Negligible numbers of participants (n<5 in each case) had accessed support through the National Disability Coordination Officer (NDCO) program and via Social Occupational and Communication Skills (SOCS) courses.

Having supports in place to help them (as necessary) identify, apply, and interview for jobs is, of course, only part of the story of successful employment for adults with high functioning ASD. Upon entering the workplace, they may be confronted with a vast array of challenges that affect their ability to perform to their full potential. Hurlbutt and Chalmers (2004) report that these challenges are likely to include comorbid mental health symptoms, sensory sensitivities, insomnia, and difficulties with social cognition and interpersonal communication.

Almost three quarters (74 per cent) of employed adults stated that they were not currently receiving any specific support at work for difficulties associated with their ASD. Of the subset of respondents who were receiving support and who provided further information about this (n=34), only five referred to receiving support from specialised workplace agencies. The majority of this group indicated that their employers were aware of their ASD, yet less than half reported having had specific accommodations and adjustments made in respect of their needs; for example:

*"They are flexible with what I can handle, e.g. they don't put me on customer service or phone work."*  
**Female, 21**

*"My boss provides specific instructions for me for my tasks, as well as informing others."* **Male, 26**

*"Instructions written and in diagram form."* **Male, 23**

*"Special lighting for sensory issues."* **Female, 24**



In a separate question, 68 per cent of respondents indicated that they would like to receive more support at work. (Respondents could answer “yes” to this question even if they had previously stated that they were currently receiving support.) As a group, when elaborating on this answer, respondents conveyed a strong desire for greater recognition, understanding and respect of their needs within the workplace by others. A further subset within this group consistently noted a need for more effective support in social skills and communication, as well as the desire to access workplace counselling.

## Unemployment

Forty-five per cent of respondents who were not in full-time education ( $n=120$ ) reported having **no paid job** at the time of completing the survey. The following analysis pertains only to this subsection of respondents.

Respondents were asked about their desire (or non-desire) for work: namely whether they would like to have a job, and if so whether they would prefer to work full-time or part-time. Figure 5.3 summarises the responses given to this question.

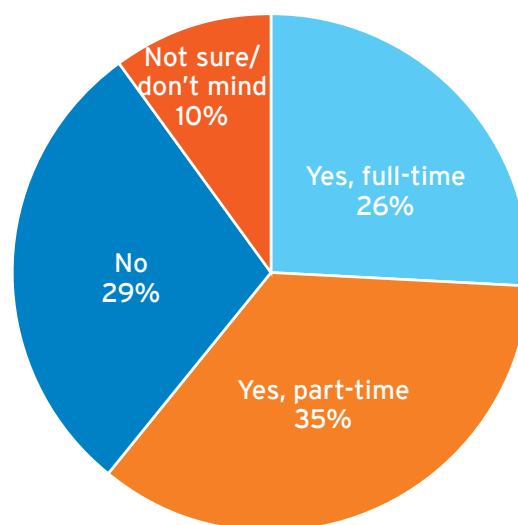
The data in Figure 5.3 imply that a reasonable majority of adults with AD and HFA who do not currently have a paid job may be described as ‘involuntarily unemployed’. Overall, 61 per cent of this group would prefer to be working, with a preference for part-time work (35 per cent) over full-time (26 per cent). Once again there is a marked contrast with corresponding statistics obtained by the ABS, which indicate that 28 per cent of Australians who are currently unemployed would like to have a job.

## Education and unemployment

Overall, the higher a respondent’s level of formal education, the less likely they were to be currently unemployed; a trend that is commensurate with general population statistics. The unemployment rate for adults with a Bachelor degree or higher qualification was 34 per cent; for those qualified to Year 12 level, 40 per cent; and for those who halted their formal education after Year 10, 69 per cent.

**Figure 5.3: Distribution of unemployed respondents by desire for work**

Respondents:  $n=114$   
Missing data:  $n=5$



## Voluntary work

Just under one-third (30 per cent) of respondents, excluding those in full-time education, reported that they were doing regular voluntary or unpaid work at the time of completing the survey. This figure is close to the national participation rate for voluntary work, reported by the ABS in 2010, of 36 per cent. The majority of this group (27 out of the 30 per cent) volunteered on a part-time basis, with just three per cent of respondents engaged in full-time voluntary or unpaid work.

## ‘Best and worst’

Following the same format as in the Education section of the survey, respondents were asked to briefly describe the ‘three best’ and ‘three worst’ things about their work and employment experiences to date. Once again, the responses were pooled, categorised and coded in line with the process outlined in Chapter 1. The outcomes of this analysis are summarised below.

### Best aspects of employment

A total of 645 positive comments relating to employment experiences were recorded in the survey, and were categorised into five key themes.

The 'top three' response themes relating to positive experiences in employment were as follows:

**1. Self-actualisation: 44 per cent of comments.** This umbrella term was used to capture responses that spoke of work as an opportunity to apply knowledge, skills and interests; to exercise independence, autonomy or creativity; to be accepted and valued, or to personally 'make a difference' in the lives of others or in society more broadly.

**2. Job roles and work content: 22 per cent of comments.** Responses were coded to this category if they referred to a general enjoyment of particular job roles and work tasks; or of positive experiences relating to broader job factors, such as the workplace environment, location or hours of work.

**3. Social and collegial factors: 19 per cent of comments.** Responses in this category spoke of positive memories of relationships and interactions with colleagues at work, as well as with members of the public encountered in the course of the job.

The remaining responses were classified under the following themes:

- » **Pay and benefits (11 per cent):** positive comments relating to earning money through work, or to other job-related benefits such as travel and 'freebies'.
- » **Negative positives (1 per cent):** comments that, whilst framed as 'positives', were in fact suggestive of negative experiences in employment. Examples include:

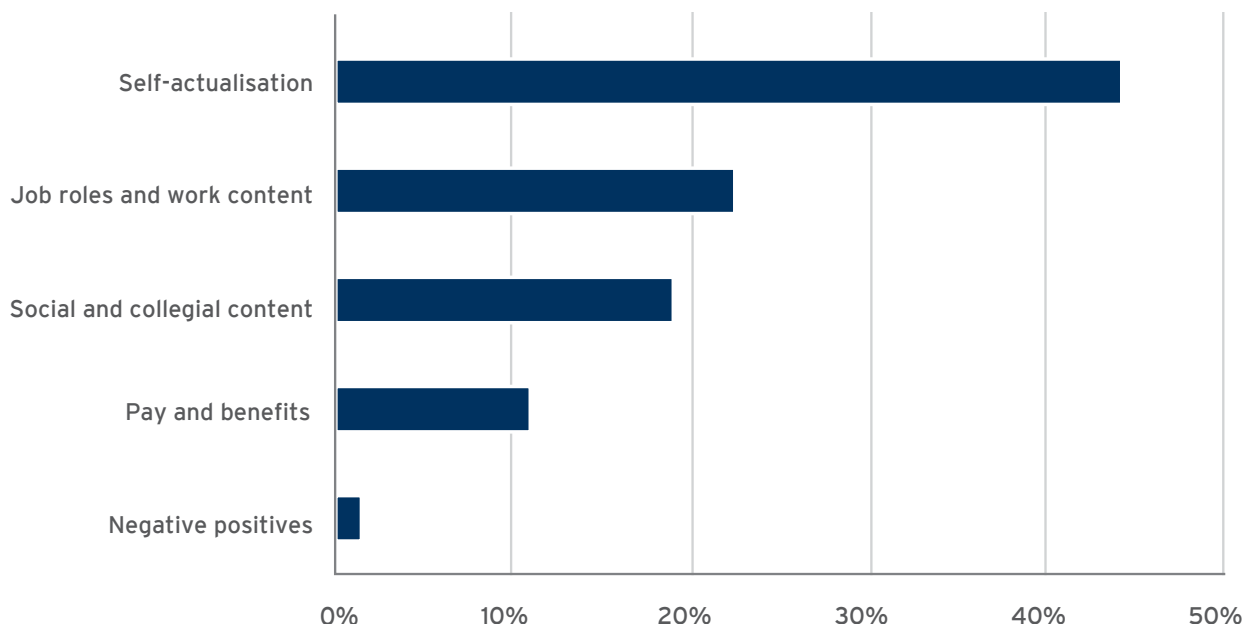
*"Realisation that some fields were just not for me."*

*"Leaving each of hundreds of hopeless jobs."*

**Figure 5.4** summarises the proportions of total positive comments about employment falling into each of these categories.

A further two per cent of responses were categorised as *other/unclassifiable*. As before, these were cases where the respondent recorded a statement that bore no relation to any of the foregoing themes, did not make logical sense, or was too vague to classify.

**Figure 5.4: 'Best' aspects of employment**



## Worst aspects of employment

A total of 568 negative comments relating to employment were recorded in the survey, and were categorised into six key themes.

The 'top three' response themes relating to negative experiences in employment were as follows:

### 1. Job roles and work content: 30 per cent of comments.

Responses were coded to this category if they referred to general dissatisfaction with job roles, work tasks, and related factors such as the workplace environment, location or hours of work. Around one-third of the comments recorded in this section recalled experiences of boring, repetitive or otherwise unfulfilling work.

### 2. Working relationships: 28 per cent of comments.

Responses in this category generally referred to perceived criticism, ill-treatment or exclusion by others in the workplace, as well as self-reported difficulties in communicating with or relating to colleagues.

### 3. Health and wellbeing issues: 20 per cent of comments.

Responses coded to this category were those that spoke of health and wellbeing concerns (including ASD-specific issues) impacting negatively on the respondent's experience of work or on their capacity to perform jobs satisfactorily.

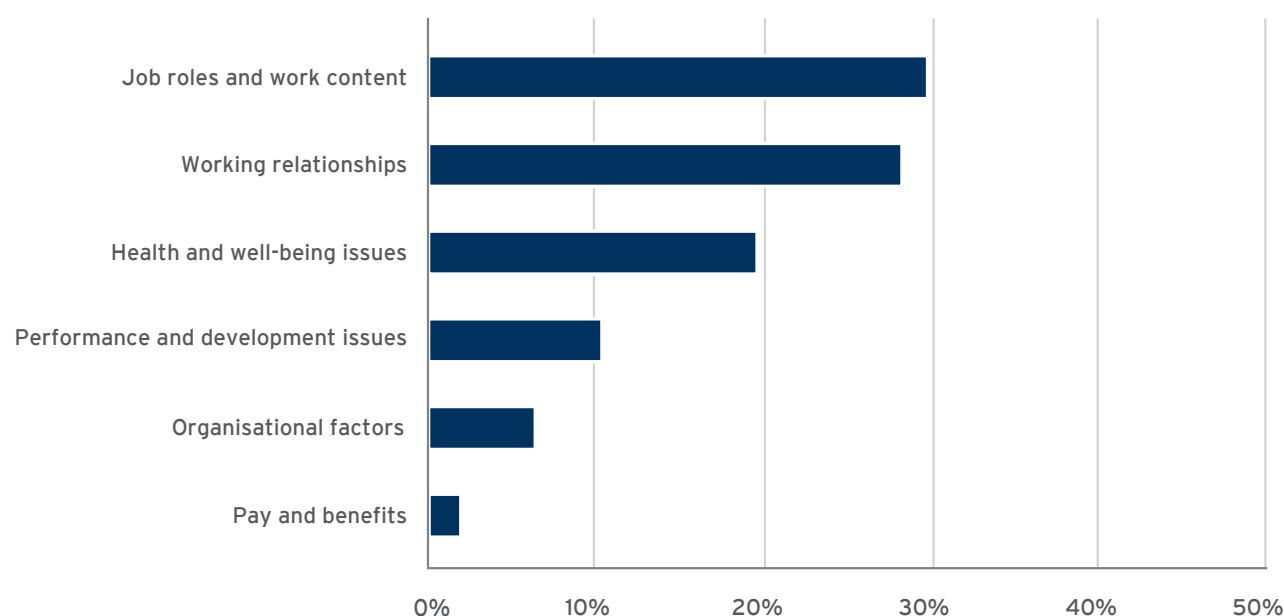
The remaining responses were classified under the following themes:

- » **Performance and development issues (11 per cent):** comments implying that the respondent had failed to fulfil his or her potential at work due to systemic or management-related factors such as a lack of adequate instruction, training or support.
- » **Organisational factors (7 per cent):** negative memories or experiences relating to generalised organisational systems and culture, including perceptions of excessive bureaucracy, staff turnover and 'office politics'.
- » **Pay and conditions (3 per cent):** comments relating to dissatisfaction with pay and conditions (e.g. leave allowances) for particular jobs.

**Figure 5.5** summarises the proportions of total negative comments about employment falling into each of these categories.

A further two per cent of responses were categorised as **other/unclassifiable** as per the definition given in the previous section

**Figure 5.5: 'Worst' aspects of employment**



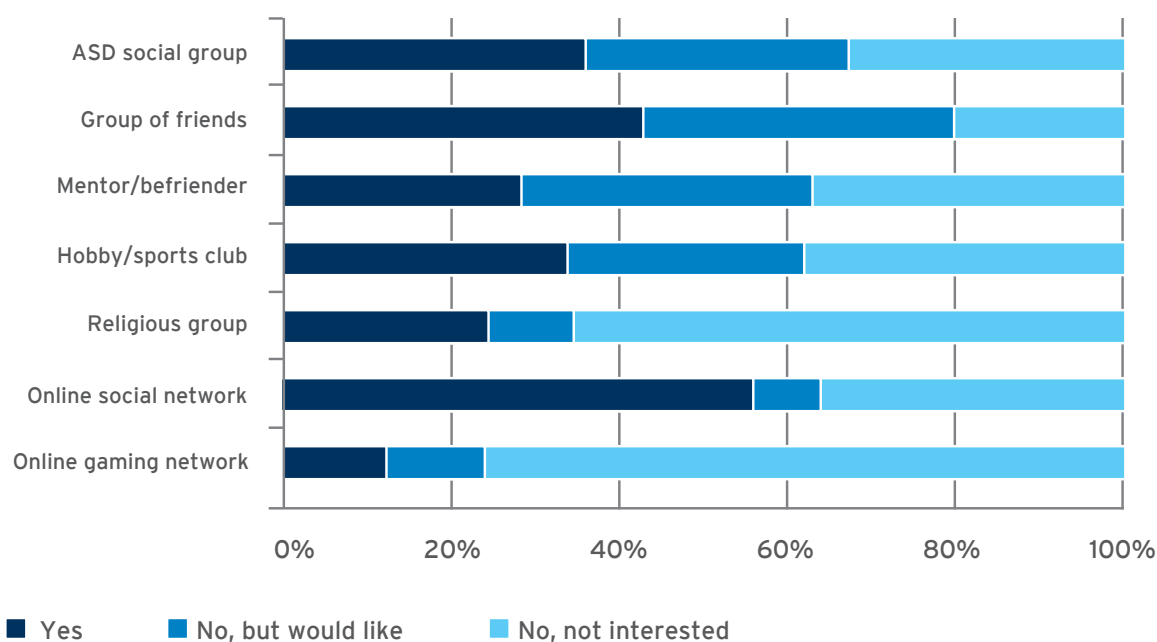
## Chapter 6: Social life

This chapter presents information on the social activities and experiences of adults with Asperger's Disorder and high functioning autism, as recorded in the We Belong survey.

### Social and community activities

Figure 6.1 presents information on the types of social groups and activities that respondents were involved with at the time of the survey, or indicated that they would like to be.

**Figure 6.1: Involvement in social and community activities**



Of the groups and activities listed, adults were most likely to be involved in an online social network, such as Facebook, Twitter or a discussion forum. Just over half (54 per cent) of respondents indicated this to be the case.

At one level, online networks might be described as an easy-access social or communal activity, with the only essential requirements for 'membership' being an internet connection and a fairly basic degree of computer literacy. It is not surprising, therefore, that only a small proportion (eight per cent) of respondents implied having experienced 'access barriers' to web-based social networks, by stating that they were not currently involved in such a network despite the fact that they would like to be.

In the context of a discussion about social and community connections, it is important to acknowledge that membership of an online social network will not necessarily equate to a satisfying social experience in any given instance. Much will depend on the extent and nature of the individual's interactions with other members of the network: and therein lies a huge spectrum of possibility, from the passive Facebook browser who never 'speaks' to another person in all their time spent online, to the enthusiastic blogger or chat-room participant who enjoys quality 'conversation' with people they consider personal friends. Precisely how an individual evaluates their online networking experiences will in turn be moderated by their expectations and desires to engage in meaningful social interaction and dialogue through these channels in the first place. These topics fell outside the scope of exploration of the current study, but remain worthy of further investigation.

Somewhat under half (42 per cent) of the adults in the study identified as having an 'informal' group of friends that met or corresponded regularly, while 35 per cent reported attending an organised social group or club for people with ASD. In both cases, levels of 'unmet need' came close to matching the proportion of adults actually engaged in these activities: 37 per cent ticked the "No, but would like to" response in relation to a friendship group, and 31 per cent for ASD social groups.

*Somewhat under half (42 per cent) of the adults in the study identified as having an 'informal' group of friends that met or corresponded regularly.*

A similar pattern of what might be characterised as 'demand versus supply' emerged in relation to the provision of one-to-one mentoring or befriending supports, and to groups based around common hobbies, interests and sporting activities. In both cases, around one-third of respondents indicated that they were currently involved in an arrangement or activity of this nature, with a further one-third stating that they were not but would like to be.

## Preferred leisure activities

Respondents were asked to describe in brief "your three favourite ways of spending your time". A total of 886 statements were generated in response to this question, and were categorised into the key themes listed and elaborated below.

The 'top three' preferred leisure activities for the study population were as follows:

**1. Cerebral activities: 15 per cent of statements.** Activities classed as 'cerebral' in nature were those whose primary purpose could be thought of as 'stimulating the mind'. Within the scope of the survey responses, these activities included reading; studying, learning and researching; and 'intellectual' discussion and debate.

**2. Miscellaneous hobbies and pastimes: 14 per cent of statements.** This category covered a wide range of responses, and was partly a 'default' classification for statements that did not fit easily into other, more specific activity descriptions. However, a common

theme running through many of the activities coded to this category was the sense of their being largely solitary pursuits. Examples included gardening; collecting things; doing jigsaw puzzles; listening to music; and cooking.

**3. Computer activities: 13 per cent of statements.** Statements coded to this category referred to various specified and non-specified computer-based activities, of which the two most commonly described were gaming and general internet usage. References to online social networking were categorised separately (see below).

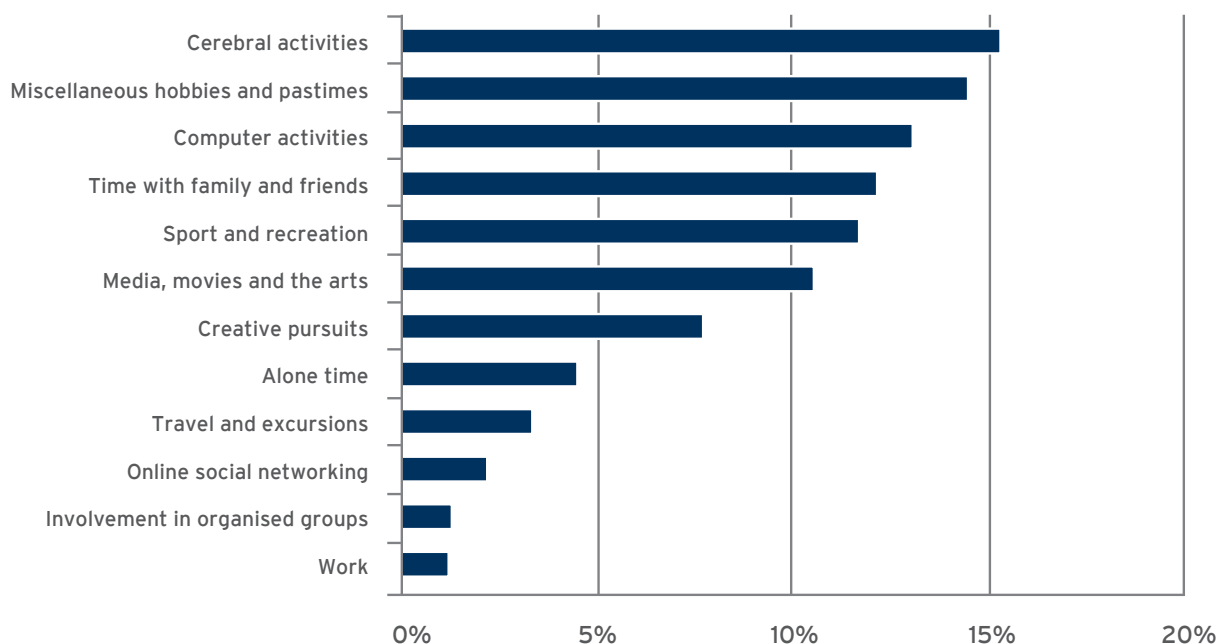
The remaining responses were classified under the following themes:

- » **Time with family and friends (12 per cent).**
- » **Sport and recreation (12 per cent):** including solo and team sports; exercise and fitness activities; and 'energetic' outdoor pursuits such as bike riding, hiking and camping.
- » **Media, movies and the arts (11 per cent):** including watching television; going to the cinema and theatre; and visiting galleries and exhibitions.
- » **Creative pursuits (8 per cent):** including art, craft and photography; creative writing; and participation in performing arts.
- » **Alone time (5 per cent):** activities that conveyed a sense of the individual wanting simply to be 'in their own space'; examples include thinking, daydreaming, sleeping, and observing or enjoying nature.
- » **Travel and excursions (3 per cent).**
- » **Online social networking (2 per cent):** references to the use of online social media channels such as Facebook, Twitter and discussion forums.
- » **Involvement in organised groups (2 per cent):** including religious, political and volunteer groups.
- » **Work (1 per cent):** a small number of statements referred to work as a preferred way of spending free time.

**Figure 6.2** summarises the proportions of responses falling into each of these categories.

A further two per cent of responses were categorised as **other/unclassifiable**. These were statements that bore no relation to any of the foregoing themes, did not make logical sense, or were too vague to classify.

**Figure 6.2: Preferred leisure activities**



## Satisfaction with social life

Respondents were asked the question: “How satisfied are you with your social life at the moment?” Figure 6.3 displays their responses. Response categories were qualified on the survey as follows:

- » **Very satisfied** – I have the amount of friends/ social activities that I want.
- » **Fairly satisfied**, but I would like to have a few more friends/social activities.
- » **Not satisfied** – I would like to have more friends/ social activities.
- » **I prefer to be by myself.**

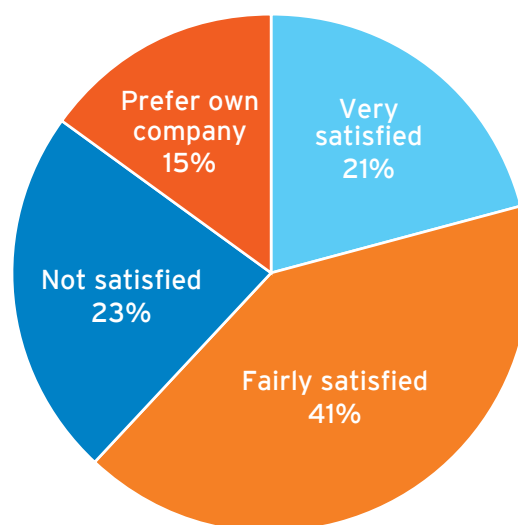
Male respondents tended to be more positive about their social life than females, with two-thirds (67 per cent) of men answering “very satisfied” or “fairly satisfied” in response to the question above, compared to just over half (52 per cent) of women. Conversely, a higher proportion of women than men (30 per cent versus 11 per cent) stated that they preferred spending time by themselves.

Further analysis revealed some significant relationships between respondents’ self-reported satisfaction with their social life and the three ‘key’

health and wellbeing concerns identified in Chapter 3: namely frequent worry or stress, mental health conditions, and communication difficulties. These relationships are indicated in Table 6.1.

**Figure 6.3: Distribution of respondents by satisfaction with social life**

Respondents: n=283  
Missing data: n=30



**Table 6.1: Experience of health and wellbeing concerns and satisfaction with social life\***

	Satisfaction with Social Life		
	Satisfied^	Not satisfied	Prefer own company
Frequent worry or stress (%)	72	90	91
Mental health condition (%)	65	85	80
Communication difficulties (%)	65	80	83

\*Comparisons of self-reported health and wellbeing concerns between 'satisfied', 'dissatisfied' and 'prefer own company' respondents were conducted using Pearson Chi-square tests and are significant for improving frequent worry or stress ( $\chi^2=13.699$ ,  $p<0.01$ ), mental health conditions ( $\chi^2=11.318$ ,  $p<0.01$ ) and communication difficulties ( $\chi^2=9.363$ ,  $p<0.01$ ).

^This category combines respondents who stated that they were 'very satisfied' and 'fairly satisfied'.

In all three cases, respondents who stated that they were dissatisfied with their social life, as well as those who stated that they preferred their own company, were more likely to report experiencing frequent worry or stress, a mental health condition, and communication difficulties than those who stated that they were satisfied with their social life.

Worry, stress, and poor mental health could feasibly represent both causes and consequences of limited social activities and relationships.

Worry, stress, and poor mental health could feasibly represent both causes and consequences of limited social activities and relationships. For example, people who are anxious or depressed may intentionally isolate themselves because they feel that they 'can't face' social situations.

Conversely, it is possible that long-running negative social experiences could over time contribute to the development of anxiety and depression. There could also be a wide range of intervening factors at play. To take just one example, an individual working in a high-pressured job may, as a result, both experience frequent worry or stress and have a less active social life than they would ideally like.

Communication difficulties, because they are an inherent part of the ASD profile and will inevitably impact on the quality of a person's interactions with others, can perhaps be more obviously interpreted as a 'cause' of a dissatisfying social life or the preference for solitude.

...an individual working in a high-pressured job may experience frequent worry and have a less active social life than they would ideally like.

# Chapter 7: Independence and daily life

This chapter presents information from the We Belong survey relating to the daily living circumstances and support needs of adults with Asperger's Disorder and high functioning autism.

## Housing and living arrangements

Previous research has shown that across the adult ASD population as a whole, relatively few individuals live in wholly independent circumstances. For example, the Wisconsin-based Adolescents & Adults with Autism (AAA) study, incorporating over 400 participants aged 10 to 53 with mild to profound intellectual disability, found that fewer than two per cent of those aged 16 and over lived in their own residence without any additional support. Just over half (54 per cent) lived with their parents, with most of the remainder living in some kind of supervised or supported accommodation, often of a communal nature (Seltzer et al., 2002).

A straightforward explanation for this finding is that individuals with an intellectual disability lack the necessary conceptual, social and practical skills

(collectively known as 'adaptive behaviour') to manage the day-to-day demands of independent living. With this in view, the **We Belong** data provide an opportunity to examine any distinguishing aspects of the housing and living arrangements of adults with ASD who do not have an intellectual disability.

Two related survey items addressed this issue: the first asked the question, "Where do you live?" (hereafter referred to as 'housing arrangements') and the second, "Whom do you live with?" (referred to as 'living arrangements'). **Table 7.1** provides a summary crosstabulation of the responses given to these two questions. The three most frequently occurring patterns of housing/living arrangement are highlighted, namely:

- » Living with parent(s) in a property belonging to the family (46 per cent).
- » Living alone in a rented property (11 per cent).
- » Living with a partner in a self-owned property (10 per cent).

**Table 7.1: Distribution of respondents by crosstabulated housing and living arrangements (per cent)**

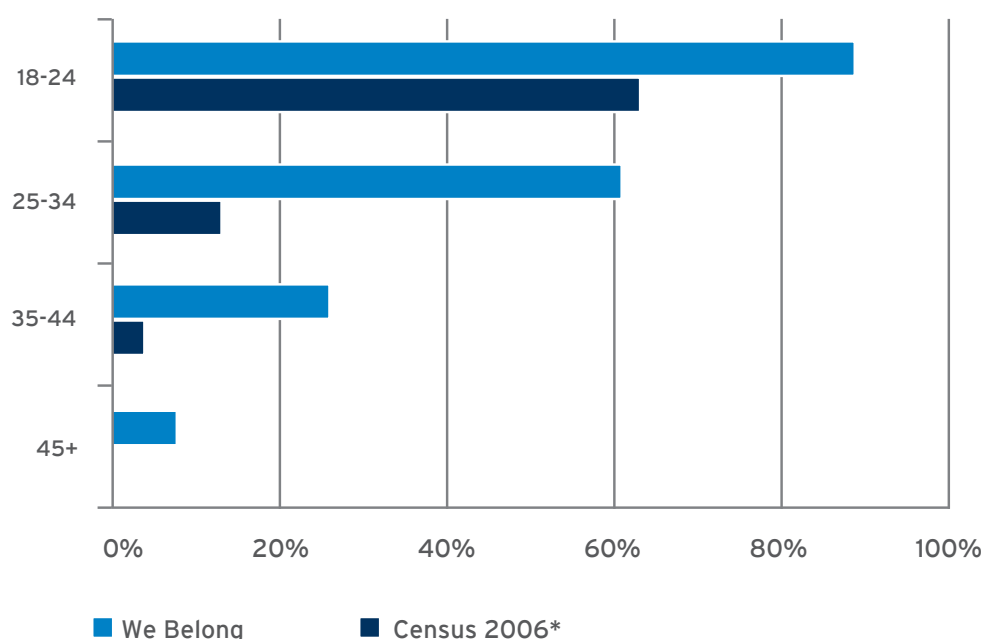
	Family property	Owned property	Rented property	Other	Total*
With parent(s)	46	1	3	1	51
With partner	1	10	4	0	16
With other family	1	0	2	0	4
With housemates	0	1	3	2	6
Alone	1	7	11	1	20
Other	0	0	1	2	3
Total*	49	20	25	7	100

Respondents: n=261

\*Totals may not match row/column sums due to rounding



**Figure 7.1: Proportions of adults living with parent(s) by age group: We Belong and Census 2006**



In a similar finding to that of the AAA study, just over half (51 per cent) of the adults in the **We Belong** sample reported living with one or both of their parents. However, there was considerable variation around this global figure by age group. Overall, the older the respondent, the less likely they were to be living with their parents. Nevertheless, a comparison of these findings with the latest available Census data (2006: see **Figure 7.1**) suggests that more adults with AD and HFA live with their parents than would be expected in a general population sample, particularly in the higher age brackets.

A small proportion (four per cent) of respondents stated that they lived with members of their immediate family other than parents. These included the respondent's children, siblings, uncles and aunts.

While 16 per cent of adults indicated that they lived with a spouse or de facto partner, 'platonic' shared living arrangements were somewhat rarer, with just six per cent of respondents living in a house- or flat-share. One in five respondents (20 per cent) lived alone.

As might be expected, there was a close correspondence between adults living with their parents and living in a property belonging to their family. The latter therefore emerged as the most common type of housing arrangement across the sample, accounting for almost half (49 per cent) of respondents. A marginal three per cent of respondents reported living in their family property alone or with people other than their parents.

Outside this group, one in five respondents (20 per cent) reported living in a property that they owned, while one-quarter (25 per cent) lived in a rented property.

Examples of housing/living arrangements falling into the 'other' categories shown in **Table 7.1** included respondents who lived:

- » in university or college accommodation;
- » in a property owned or rented by the respondent's partner;
- » in a communal residential facility, including supported and retirement accommodation;
- » with a landlord in private lodgings;
- » in flexible or unofficial arrangements (e.g. 'couch surfing').

In summary, the survey data reveal that adults with AD and HFA are more likely to live with their parents than adults in the population at large, and are not necessarily any less likely to live with their parents than adults who have an intellectual disability as part of their ASD. However, amongst those living away from their families, there is a notable level of independence with regard to housing and living arrangements that is not seen within the broader ASD population or other disability cohorts. Only  $n=3$  participants in the entire sample reported that they lived in supervised or supported accommodation.

## Satisfaction with housing/living arrangements

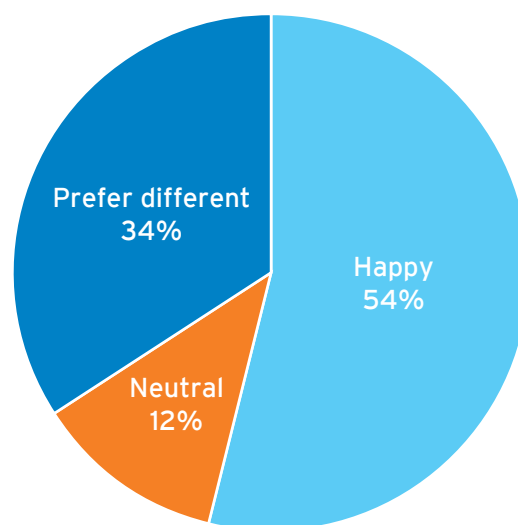
Respondents were asked how they felt about their current housing and living arrangements: namely whether they were happy, neutral (had no strong feelings one way or the other), or would prefer a different arrangement. **Figure 7.2** displays the responses given to this question.

Respondents who stated that they would prefer a different housing and/or living arrangement ( $n=109$ ) were asked to briefly elaborate on what they would like to change about their current circumstances. The largest proportion of respondents in this group (26 per cent) indicated a desire for greater independence in their housing or living arrangements, such as moving out of their parents' home or buying their own property. The remaining preferences were fairly evenly divided between the desire to live with other people (18 per cent); in a different geographical location (17 per cent); in a different type of housing and/or with improved facilities (16 per cent); and alone (16 per cent).

**Figure 7.2: Distribution of respondents by satisfaction with housing/living arrangements**

Respondents:  $n=310$

Missing data:  $n=3$



## Family support

As a whole, the adults in the study were very positive about the support they had received, and continued to receive, from their families. Large majorities of respondents answered “Yes, definitely” or “Yes, to some extent” in response to the following statements, as below:

- » “At least one member of my family understands my needs”: 81 per cent
- » “There is at least one member of my family whom I can always turn to for help if I need it”: 78 per cent
- » “At least one member of my family has helped me to access professional support”: 77 per cent.

## Financial assistance

Adults with ASD may be eligible for a range of statutory benefits, such as the Disability Support Pension and other payments relevant to their individual circumstances. A little over half (56 per cent) of respondents stated that they were in receipt

of regular financial support of this kind. Just over one-quarter (26 per cent) stated that they received regular financial support from their parent(s).

## Support needs

Towards the end of the survey, respondents were presented with a table listing a range of potential areas of support for independence and everyday living, and asked to select one of the following responses in relation to each:

- » I am already getting enough support with this.
- » I need more support with this at the moment.
- » I think I will need more support with this in the future.
- » I don't need any support with this.

Responses to this question are reviewed thematically in the following sections. In each case, the first and last response options listed above have been combined, creating a single response category that denotes no additional support is required in that area.

## Everyday independence

**Figure 7.3** presents data on respondents' self-reported support needs in areas relating to general independence and skills for everyday living.

Overall, the responses displayed in **Figure 7.3** reinforce the 'high functioning' nature of the population being surveyed in this study. A large majority (91 per cent) of respondents stated that they did not require any special support with day-to-day personal care, such as washing and dressing; and just over two-thirds (68 per cent) gave this response in relation to the support area of 'cooking or housekeeping'. Similarly, the majority (88 per cent) indicated that they did not need any special assistance with taking medication; presumably because they either felt capable of managing their medication regimes themselves, or did not need to take regular medication.

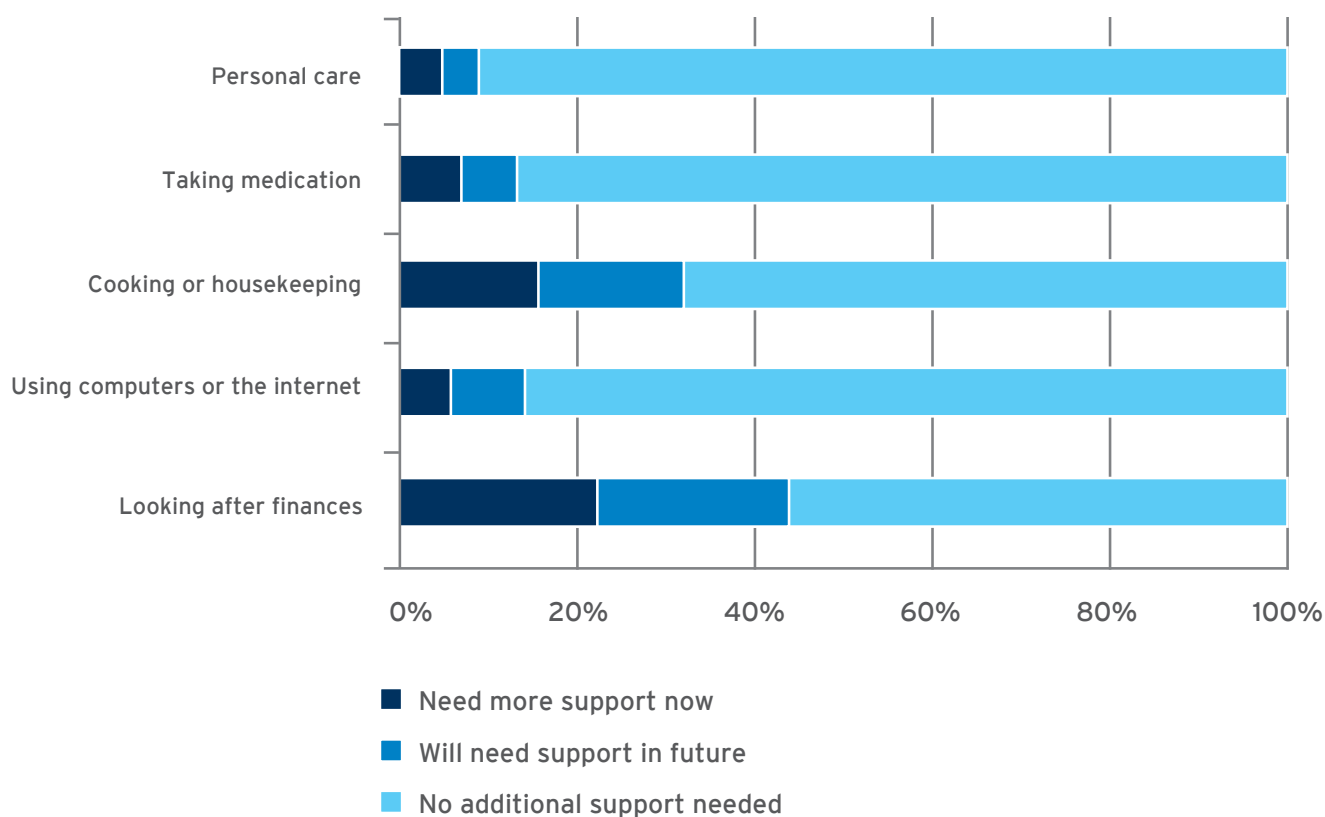
The popular conception of individuals with ASD as being technically adept is borne out by the finding that 88 per cent of respondents identified no current or future support needs in relation to using computers or the internet.

Respondents were somewhat more likely to indicate support needs in relation to managing their personal finances: 22 per cent stated that they needed more support now with looking after their financial affairs, and the same proportion considered that they were likely to require support with this in the future.

## Driving

Not shown in the chart above, a further 'life skill' that many adults with AD and HFA do not appear to unduly struggle with is driving. In a separate question on the survey, 60 per cent of respondents reported having a current driver's licence. A further 11 per cent of respondents were taking driving lessons at the time of the survey.

**Figure 7.3: Support needs for everyday independence**



## Study, work and housing

**Figure 7.4** summarises respondents' self-reported support needs in the areas of education, employment and housing.

A common factor across the domains shown in **Figure 7.4** is that they all require some degree of motivation, initiative, organisation, and high level information processing. In many cases they will also involve communications and interactions with 'unknown others', such as administrative and teaching staff in education settings, prospective employers, and real estate agents. The cognitive and social demands underlying these tasks may present considerable challenges to adults with ASD.

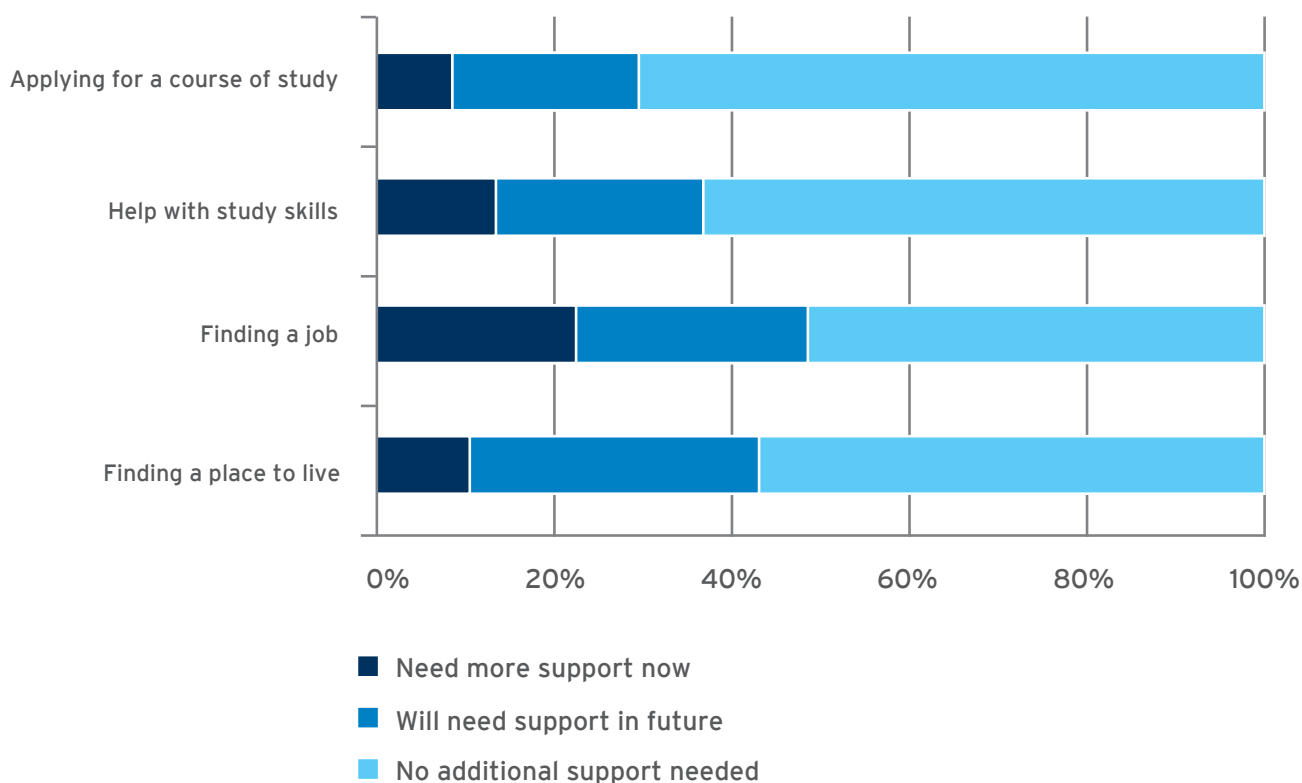
At a global level, survey respondents demonstrated a reasonable level of independence across the four areas listed in **Figure 7.4**, with over half in each case reporting no current or projected future support needs. Respondents were most likely to indicate additional support needs in the area of finding a job (48 per cent), followed by finding a place to live (43 per cent), study skills (36 per cent), and applying for a course of study (28 per cent).

However, it must be borne in mind that these questions will have been more applicable to certain subsets of participants than others by virtue of their personal circumstances. The following breakdowns of the data are thus potentially more instructive:

- » 63 per cent of adults who were *unemployed* wanted support to find a job.
- » 66 per cent of adults who *lived with their parent(s)* wanted support to find a place to live.
- » 42 per cent of adults who were *enrolled in education* wanted help with study skills.

In addition, there was a significant link between respondents' past experiences of learning support and their current desire for help with their study skills. Almost half (48 per cent) of respondents who reported insufficient learning support during their time in education stated that they now needed support with study skills, in contrast to just over one-third (34 per cent) of those who believed they had received adequate support.

**Figure 7.4: Support needs for study, work and housing**



## Social life and relationships

**Figure 7.5** summarises a range of support needs expressed by respondents within the domain of social life and interpersonal relationships.

Given that social interaction and communication deficits represent two of the defining features of ASD, it is not surprising that the adults in this study indicated relatively high levels of need for current or future support in the three areas shown: 60 per cent for improving social skills, 51 per cent for dating and relationships, and 46 per cent for explaining autism to other people.

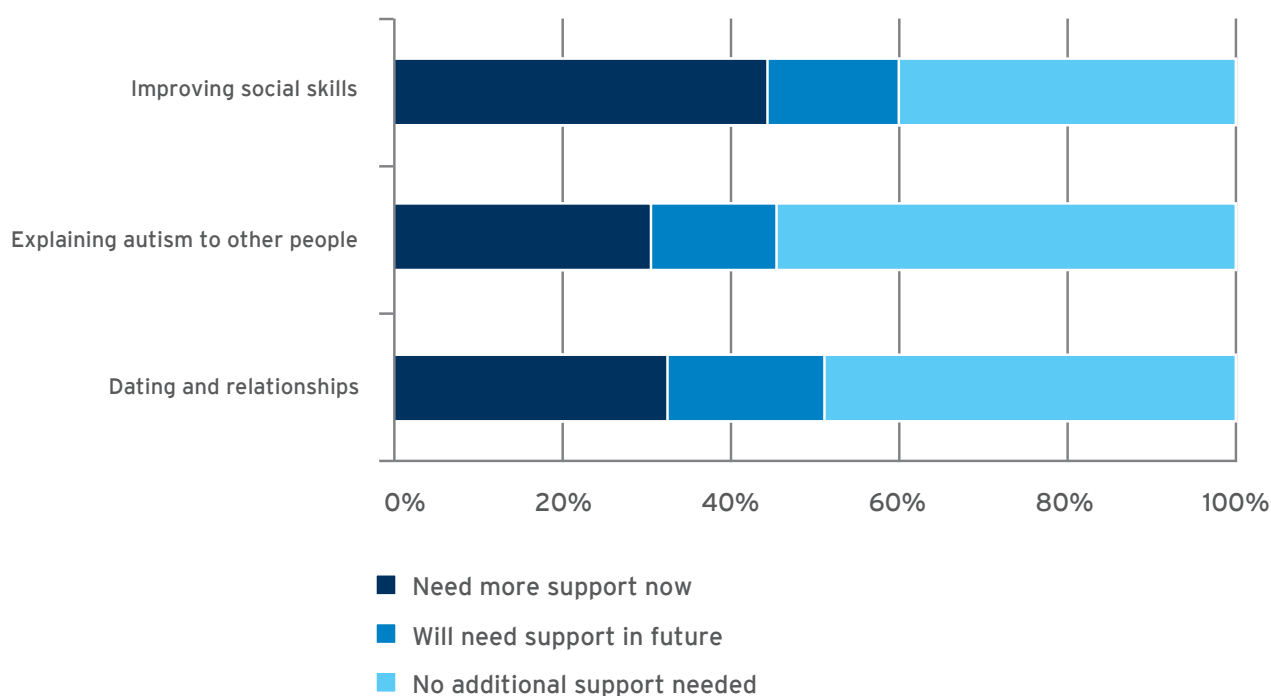
Further analysis showed a strong connection between the level of social support received during respondents' education years and their subsequent expression of need for support with social skills. Seventy-one per cent of respondents who retrospectively reported insufficient social support in education settings stated that they now needed support to improve their social skills.

The corresponding figure for those who felt they **had** received adequate support was significantly lower, at 37 per cent.

Whilst 'dating and relationship support' is a wide-ranging term, and one that could include support appropriate to individuals already in a romantic relationship (e.g. marriage counselling), it may have particular resonance for those who are single and seeking opportunities to meet potential partners. On these grounds, it is noted that amongst respondents who were neither married nor in a de facto or dating relationship at the time of the survey, the proportion expressing a desire for dating and relationship support increased to 64 per cent.

The issue of 'explaining autism to other people' may reflect both a need for improved self-understanding and communication skills on the part of adults with ASD, and - perhaps more significantly - a pervasive lack of awareness, knowledge or tolerance on the part of 'other people' with regard to autism, which needs to be addressed.

**Figure 7.5: Support needs for social life and relationships**



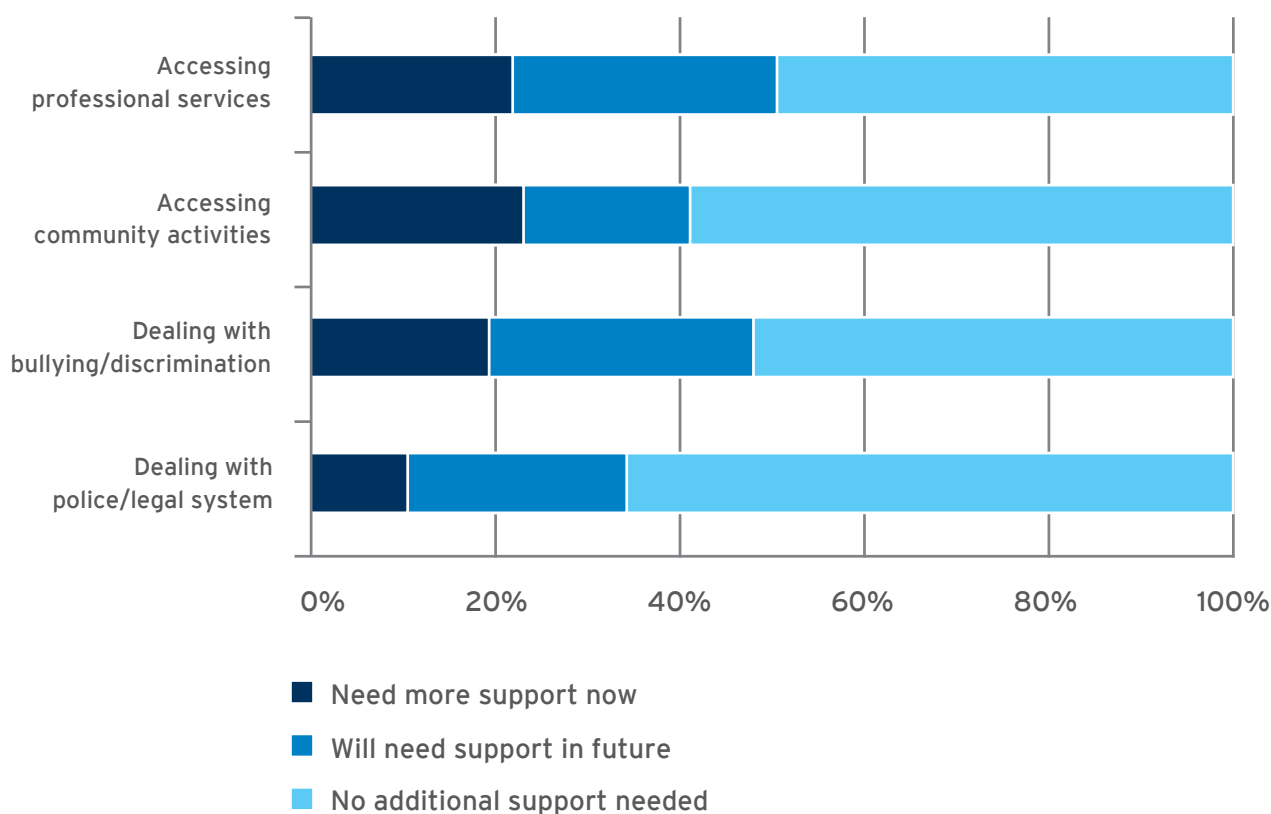
## Community life and social citizenship

The final subset of support needs listed in this section of the survey were those that pertained broadly to life in the community and to public and professional interactions in a number of contexts. Figure 7.6 summarises the self-reported support needs of respondents in these areas.

As a group, respondents indicated moderate levels of support need across these four areas. Of particular note is the finding that almost half (47 per cent) identified a need for support, either now or in the future, to deal with issues of bullying or discrimination. This highlights once again that for the adult ASD population (if not more widely), bullying is not a problem that gets left behind in the schoolyard, and is serious enough that adults need to appeal to external sources of support to help them address it.

Almost half (47 per cent) identified a need for support, either now or in the future, to deal with issues of bullying or discrimination.

**Figure 7.6: Support needs for community life and social citizenship**



## Chapter 8: Future aspirations

In the final section of the survey, respondents were asked to briefly describe up to three things that *“you would most like to do, achieve or see happen in your life in the future”*.

A total of 757 ‘aspirational statements’ were recorded in response to this question, and were categorised initially into 15 key themes. Following a review of the response distributions across these categories, a number of the themes were combined in order to create broader conceptual groupings that would elicit more meaningfully sized ‘clusters’ of responses.

A total of 757 ‘aspirational statements’ were recorded in response to this question, and were categorised initially into 15 key themes.

The ‘top three’ response themes to the question *“What would you most like to do, achieve or see happen in your life in the future?”* were as follows:

### **1. To be more fulfilled socially and relationally: 23 per cent of aspirational statements.**

Answers were coded to this theme when the respondent expressed a desire or hope to:

- » improve their social skills or social life: for example, to be better at making conversation or to gain more friends;
- » maintain or improve existing relationships in their life, or to restore relationships that had been damaged or broken;
- » form a romantic relationship, get married and/or have children.

### **2. To make a positive contribution through work suited to interests and skills: 19 per cent of aspirational statements.**

Answers were coded to this theme when the respondent expressed a desire, hope or ambition relating to their job, working life or career. For example:

- » to get a (new) job;
- » to become more proficient at their current job;
- » to attain greater job satisfaction;
- » to be promoted or otherwise progress their career;
- » to set up their own business.

In addition, statements indicating more abstract or idealised career-related goals were also coded to this theme. Examples drawn from the survey data included the ambition to write a song, publish a novel, and develop a new invention.

### **3. To maintain or improve physical and mental health and everyday wellbeing: ten per cent of aspirational statements.**

Answers were coded to this theme when the respondent expressed a desire or hope to:

- » maintain or improve aspects of their physical health and functioning;
- » maintain or improve their day-to-day mental wellbeing: for example, to be happier, to feel that they were ‘coping’ better, or to develop their self-awareness, self-understanding or self-acceptance;
- » overcome, or better manage, a current mental health condition.

The remaining aspirational statements were classified under the following themes:

- » **Housing and living arrangements (9 per cent).** Desires or hopes pertaining to the individual’s housing or living circumstances: commonly these statements referred to owning a property and/or moving to a new geographic location.
- » **Hobbies, leisure and travel (9 per cent).** Statements related to the pursuit of personal hobbies, interests and leisure activities, including travel.
- » **Ideological goals (9 per cent).** Desires or hopes for large-scale social or political change, or the advancement of public or scientific knowledge, particularly in relation to ASD.

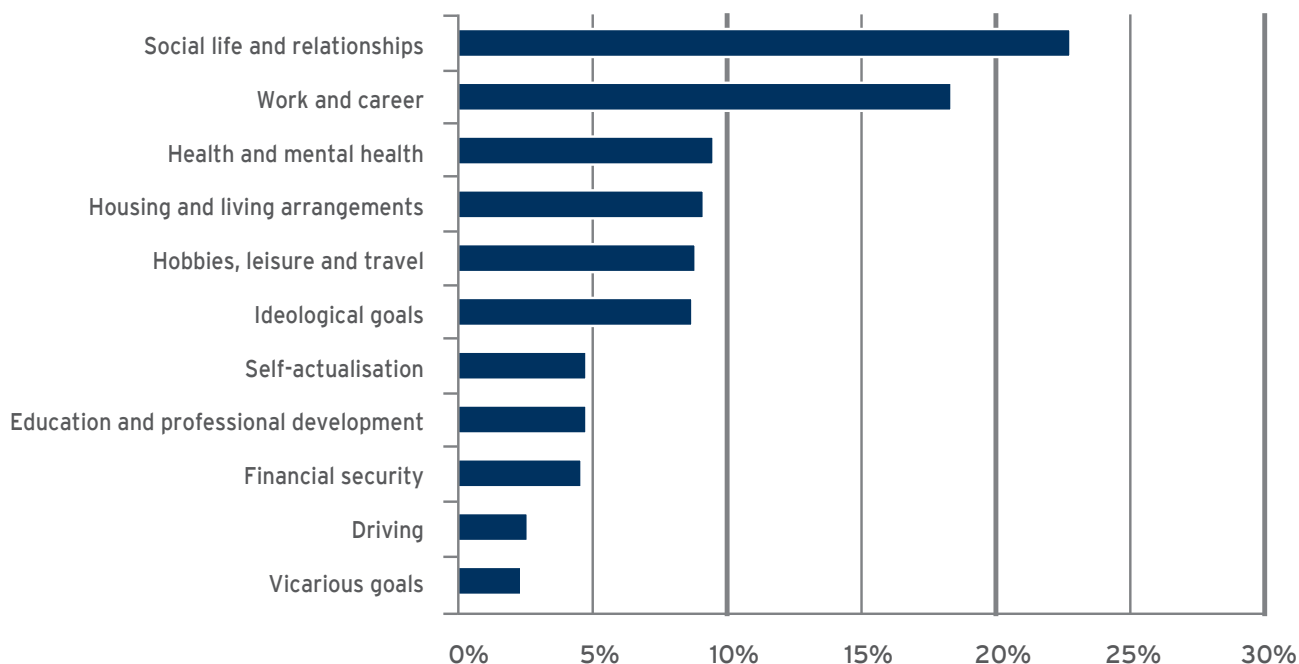
- » **Self-actualisation (5 per cent).** Statements related to maintaining or achieving personal dignity, independence, acceptance, recognition or success.
- » **Educational and professional development goals (5 per cent).** Desires, goals and ambitions related to studying, gaining educational qualifications, or developing professional skills via formal training.
- » **Financial security (5 per cent).** Desires, goals and ambitions related to wealth accumulation and/or general financial security.
- » **Driving (3 per cent).** Statements in which respondents expressed a desire or hope to obtain a driver's licence, improve their driving skills, or to do more driving.
- » **Vicarious goals (3 per cent).** Statements that expressed desires, hopes or ambitions on behalf of other people or groups: most commonly family members, but occasionally celebrities or sporting teams.

Figure 8.1 shows the percentage of aspirational statements falling into each of these categories.

Two residual categories of responses are not shown in Figure 8.1. These are:

- » **Other/unclassifiable (2 per cent of responses)** – where the respondent recorded a statement that bore no relation to any of the foregoing themes, did not make logical sense, or was too vague to classify.
- » **Not applicable (<1 per cent of responses)** – where the respondent expressly stated that they had no specific hopes or ambitions for the future, and/or that they preferred not to plan for or predict future events.

**Figure 8.1: Future aspirations**





# Chapter 9: Discussion of findings

This final chapter reviews the key themes emerging from the **We Belong** study data to develop a generalised 'pen portrait' of the past experiences, present circumstances, and future aspirations of adults with AD and HFA in Australia.

## Aspirations and goals

The **We Belong** study has confirmed that adults with AD and HFA have aspirations and goals for their lives that accord with established 'quality of life' indicators (Schalock, 2000) and are similar to those held by many other Australians. They want to be physically and emotionally healthy; to be engaged in fulfilling and meaningful employment; and to have a range of successful social relationships, including if possible a life partner.

*...there is evidence of an ongoing need for both professionals and the general public to be better informed about autism...*

If adults with AD and HFA are to have a fair chance of achieving their aspirations and goals, they will need to have access to appropriate professional services and supports, examples of which are detailed in the following sections. More broadly, there is evidence of an ongoing need for both professionals and the general public to be better informed about autism as a significant step towards adults with the condition being understood, accepted and supported within their networks and communities.

## Service access, expertise and integrity

Notwithstanding their intelligence and capabilities, adults with AD and HFA face a diversity of ongoing support needs that are not always recognised for the very real and crippling challenges that they are or can become. Accordingly, this group require access to services with appropriate levels of 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.

At present, 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. Given their particular challenges with interpersonal interaction and information processing, this group may also need specific guidance and help to navigate their service options and to identify, make contact and communicate with relevant organisations and their staff.

## Health and wellbeing

Mental health is a significant area of concern for adults with AD and HFA. In addition to a high prevalence of 'clinical' mental health conditions within this population, a majority experience ongoing feelings of worry and stress, which only appear to worsen with age. More concerning still is the finding that many adults with AD and HFA who suffer from poor mental health are not receiving enough, if any, professional support to help them manage these conditions. There is a strong desire within this group for access to counselling and psychology services and support groups; however, against their wishes, substantial numbers currently have no contact with these services.

## Education

It is evident that many of today's adults with AD and HFA went through childhood as keen learners and continue as such in adulthood. Formal study is regarded by this group not only as a means to an end, but as a valuable and rewarding endeavour in its own right; likewise the more informal pursuit of knowledge and intellectual development through reading, researching topics of interest, and engaging in 'cerebral' discussion and debate with others. Whilst these traits and preferences are by no means peculiar to the ASD population, they may have special significance as a reflection of the intense and specific special interests often exhibited by adults with AD and HFA, to which they may devote immense amounts of time and energy. The largely solitary nature of studying and learning may also hold special appeal for adults who, either by preference or default, have less social contact than their neurotypical peers.

Overall levels of educational attainment are high relative to the general population, though rates of university completion lag behind the national aggregate.

In spite of their inherent interest in and aptitude for study, adults with AD and HFA have experienced significant struggles to reach their full potential in education. A clear implication of the **We Belong** findings is that the absence of an intellectual disability does not equate to an absence of learning support needs. Verbal comprehension appears to be an area of particular concern for high functioning students with ASD, who, due to their various cognitive deficits, may struggle to maintain concentration, keep up with the pace of oral teaching, understand abstract language or illustrations, make inferences, or 'hone in' on salient information necessary for successful task completion (Costley et al., 2012). These and other challenges within the education environment may contribute to psychosomatic symptoms such as stress, fatigue and anxiety, and in some cases lead to abandonment of courses of study altogether, in turn heightening the risk of future unemployment.

*A clear implication of the We Belong findings is that the absence of an intellectual disability does not equate to an absence of learning support needs.*

Many adults with AD and HFA failed to have these needs properly understood or met while at school, and continue to require support in adult education to cope with the demands of formal learning. It appears there is an ongoing need to develop awareness and skills amongst teachers and other educational staff to work with students with ASD; in particular, to dispel misconceptions and stereotypes about autism that may lead to high functioning students having their support needs overlooked or disregarded because they do not fit into conventional social constructions of 'disability'.

Another huge blight on the educational experiences of adults with AD and HFA has been the victimisation and exclusion they have endured at the hands of fellow students; and, in some cases, teaching staff. These traumatic incidents have often sat alongside a general sense of isolation borne out of their difficulties understanding, relating to, and communicating with others; the scars of which evidently run deep and are linked to ongoing social support needs in adult life.

## Employment

Like many people, adults with AD and HFA view work as an opportunity to apply their knowledge, skills and interests in a way that is personally rewarding and has intrinsic value. However, their capacity to find and maintain employment that is suited to their qualifications and strengths may be hampered by the comprehension, communication and relational challenges of seeking, applying and interviewing for jobs; and by the failure of many workplaces to provide accommodations and adjustments appropriate to the individual's cognitive, health and social needs. The social and collegial demands of the workplace represent one of the greatest challenges for adults with ASD and an area of extreme vulnerability, which cannot be compensated for by superior intelligence or job skills.

These predicaments may go some way to explaining not only the high unemployment rate within the study population, but their overrepresentation in part-time and casual positions of employment. Whilst part-time work can (at least for some) be as much a lifestyle choice as a coping strategy, casual work may hold significant disadvantages for an intellectually capable adult with ASD. In the first place, it is often comparatively low-skilled and poorly paid, with limited opportunities for training and career development. Furthermore, a high proportion of casual jobs are found in primarily 'people-facing' industries, such as retail and hospitality, which may create special anxiety and discomfort for adults with AD and HFA.

## Social life

It is clear that, contrary to some stereotypes, adults with AD and HFA do not necessarily 'prefer their own company'. There are a number of elements of the **We Belong** study findings that support this assertion.

- » Spending time with family and friends emerged as one of the top five preferred leisure activities for participants in this study.
- » Some of the adults' happiest memories of education and the workplace are centred around the friendships, social interactions and collegiality enjoyed in those settings.
- » At least as many respondents would prefer to switch their current housing arrangements to living with other people as to living alone.
- » As a group, reflecting on their greatest hopes for the future, the desire for social and relational fulfilment outweighed career ambitions, health ideals, and a wide range of other, more self-focused aspirations.

Yet in spite of their inherent desire for companionship and social connectedness, many adults with high functioning ASD 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. The experience, or at least anticipation, of bullying and discrimination at the hands of others remains very real even into adulthood.

*Accordingly, adults with AD and HFA would welcome better availability of and access to social supports, including one-to-one mentoring...*

Accordingly, adults with AD and HFA would welcome better availability of and access to social supports, including one-to-one mentoring or befriending, organised social groups, and groups centred around common hobbies and interests. The self-report data pertaining to preferred leisure pursuits provide clues as to the kinds of social and community activities likely to prove popular with this group.

## Independence and daily life

Whilst on the whole adults with AD and HFA do not exhibit the same adaptive behaviour deficits as individuals with a global intellectual disability, there are many ways in which their everyday independence is restricted relative to the neurotypical population. Difficulties with high level information processing, flexible thinking, personal organisation, and interpersonal relating, compounded by ongoing mental health issues, can present challenges across a range of 'life management' areas: from keeping on top of personal finances, to seeking medical assistance, to getting on the property ladder. It is perhaps for these reasons that a disproportionately high number of adults in this group continue to live with their parents well into adulthood.

## Conclusions and next steps

At present, adults with AD and HFA in Australia face significant personal, social, and professional barriers to fulfilling their potential as intelligent and independent members of society. Caught in spirals of social isolation, poor mental health, and over-dependence on family support, they experience ongoing challenges to integrate and participate in their networks and communities.

The vision articulated by the **We Belong** participants is for a society in which adults with AD and HFA are better understood and accepted, have their ability to contribute professionally and socially more clearly recognised, and are valued rather than stigmatised for their differences.

**We Belong** establishes the need for further research, development and delivery of policies and services that may include:

- » Explicit recognition and inclusion of this group in disability funding programs, such as the National Disability Insurance Scheme (NDIS).
- » ASD-specific transition to work programs that will contribute to economic participation.
- » Community-based social groups, one-to-one mentoring and befriending programs that will develop life skills and foster social inclusion.
- » Peer education programs in schools, TAFE institutes and workplaces to increase public awareness and acceptance of people with ASD.
- » ASD-specific counselling and psychology services and support groups that will contribute to improved mental health and wellbeing.
- » Case management and advocacy services to support and guide individualised choice of service options for adults with AD and HFA and their families.
- » Increased provision and visibility of education, training and resources for professionals and service providers who work with the AD and HFA community.

A new suite of responsive services and supports will give this forgotten group of people the recognition and opportunities that their talents warrant and their human dignity demands.

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## 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](http://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)**