



Autism Spectrum Disorder: Public awareness and attitudes



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Introduction

Autism Spectrum Disorder (ASD) is the term used to describe pervasive developmental disorders diagnosed in the presence of atypical behaviours in social interaction, social communication and social imagination. Prevalence rates have been rising sharply and are estimated to be 1:88, and 1 in 50 amongst children. Boys seem to be affected more frequently than girls.

In Northern Ireland, the Autism Act (NI) 2011 amended the Disability Discrimination Act 1995 by including in the definition of disability people who have impairments with regard to taking part in typical social interaction or forming social relationships. The Act also mandated the development of a cross-departmental Autism Strategy to be published no less than two years within the passing of the Act.

Against the backdrop of this political context, a module on autism was included in the **Northern Ireland Life and Times (NILT)** survey in 2012. This Research Update uses results from this module to provide a timely measure of public awareness of, and attitudes towards, individuals with autism prior to the implementation of the Autism Strategy.

Autism awareness

Autism awareness was much higher than expected: the vast majority of NILT respondents (82%) stated that they were aware of autism, Autism Spectrum Disorder, or Asperger's Syndrome, while only 16 per cent were unaware and 2 per cent were unsure. The remaining questions in the autism module were asked of those respondents who had heard of autism.

Each participant was asked to list the main strengths and difficulties that they thought

were associated with autism. Responses to these questions are displayed in word clouds, where the size of the text indicates how often a specific word was used by respondents to describe their awareness of an issue. Only words that were used by at least ten respondents are included in the word clouds.

The strengths that participants associated with autism are shown in Figure 1, and these included being intelligent/very intelligent, having a special talent, creativity, good memory and being good at art, music or maths. Non-academic strengths such as being loving, focused and determined were also mentioned. A number of participants commented that they were unsure what the strengths of autism are, or that they felt that there is variation in strengths amongst individuals with autism. Just over one third of respondents did not answer this question.

Special abilities are relatively infrequent

amongst individuals diagnosed with autism, estimated to occur in 1:200 individuals with autism. As shown in Figure 1, special talent was cited by a relatively small number of participants as a strength associated with autism. Nevertheless, when asked specifically if they thought that individuals with autism have a special talent, the majority of respondents in the NILT sample responded either definitely or probably (84%).

When asked to name the difficulties associated with autism, respondents correctly identified many of the core features of autism including communication, social, behavioural, and interaction difficulties (see Figure 2). Respondents also rightly identified that individuals with autism are likely to have difficulties in areas of life such as understanding other people's feelings, being understood, dealing with changes to routines, integrating into society, being independent, and concentration. A

Figure 1: Strengths the public associated with autism

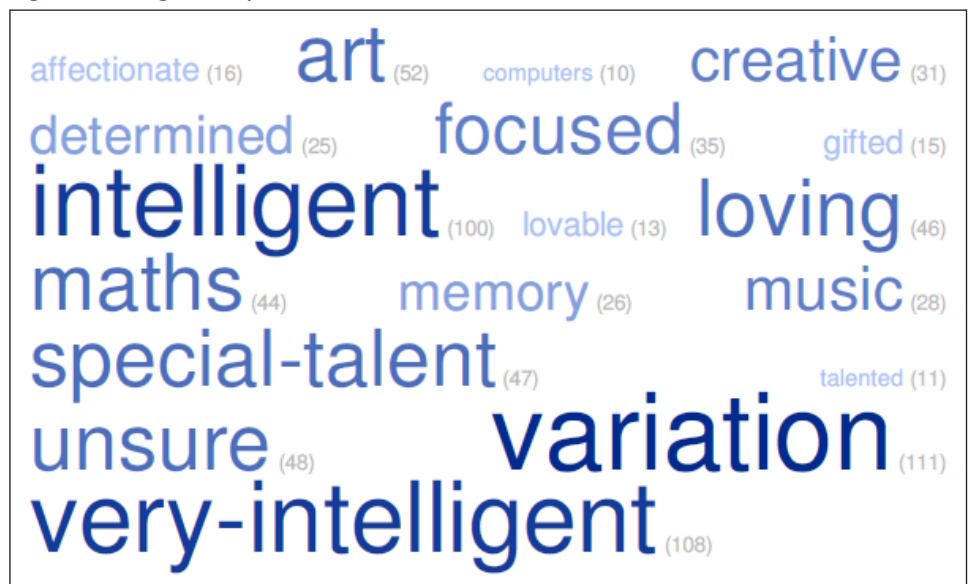
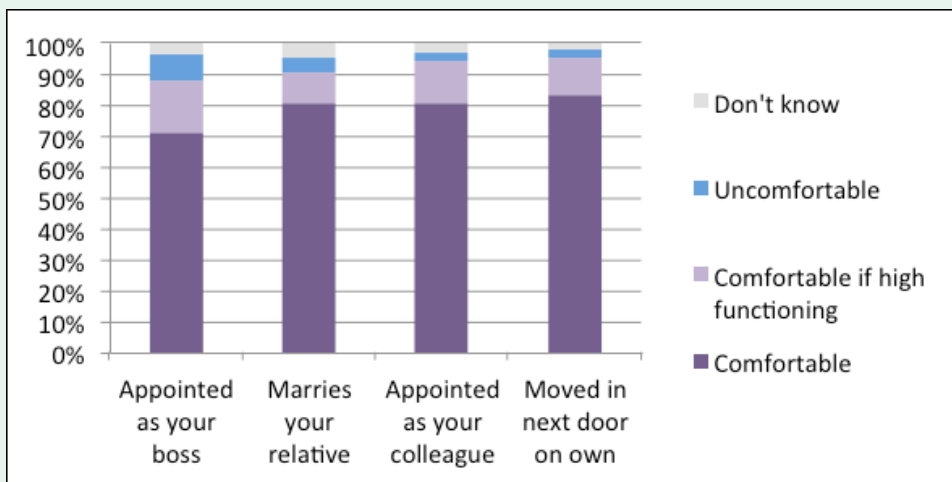


Figure 2: Difficulties which the public associate with autism



Figure 3: Views on adults with autism in social situations and employment



small number of participants thought that there could be variation between individuals with autism in terms of the difficulties that they experience. Approximately one in eight respondents (13%) did not answer this question.

More than three fifths of the participants (61%) said that they knew someone with autism. Of these, 19 per cent had a close relative or other family member with autism, 40 per cent had a friend or acquaintance, and 8 per cent had a work colleague with autism; one individual with ASD completed the survey. However, 39 per cent of respondents said that they did not know or were unsure if they knew someone with autism.

Adults with autism

Only about 15 per cent of adults with autism are in full time employment (Stewart, 2008). The consequences of unemployment of individuals with autism are considerable for the individual themselves and for the economy in general, representing 36 per cent of the estimated annual cost of autism in adults in the UK of £25 billion (Knapp et al., 2009).

In fact, 68 per cent of individuals with autism continue to live with their parents into adulthood (Dillenburger and McKerr, 2011). This can be stressful for ageing parents. It is estimated that unpaid family care saves the UK taxpayer an annual £87 billion, a sum that

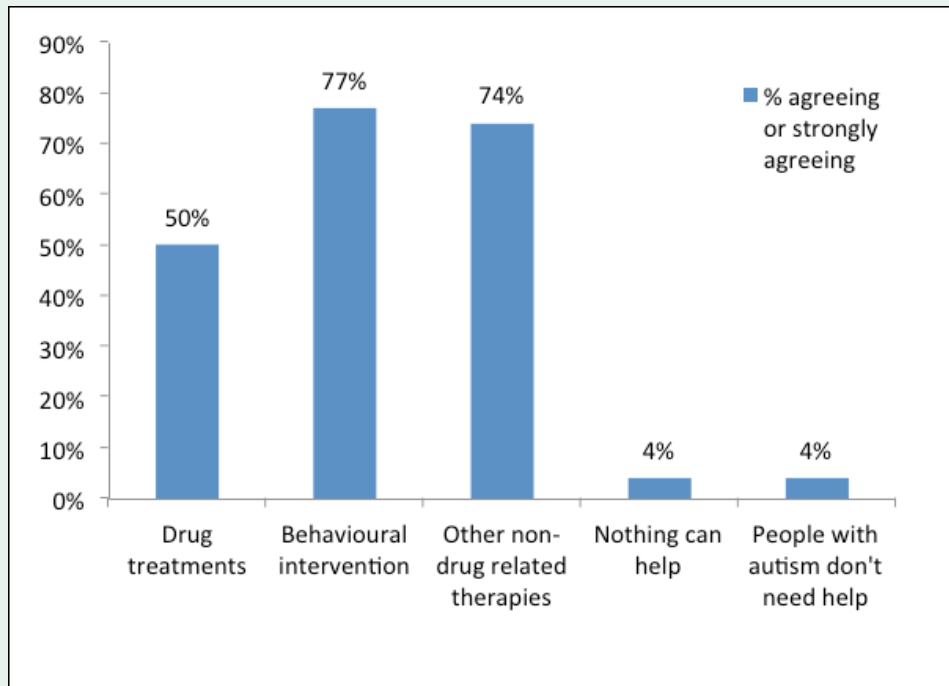
exceeds the total expenditure on the NHS.

Employment is obviously the best way to ensure financial independence and social inclusion for adults with autism. While most individuals with autism are not in employment, they are generally willing and able to work providing necessary supports are in place (NAS, 2013). Of course, the choice of jobs depends on levels of ability but it has become clear that employment opportunities for individuals with ASD are not limited to professions that focus on repetitive or systematic skills. Individuals with ASD can obtain employment in socially demanding occupations. Increasingly, their skills are recognised in industry, and some businesses focus specifically on employing individuals with ASD (for example, www.spectrumdesigns.org). In contrast, without appropriate support most individuals with autism find it hard to obtain employment and jobs tend to be unskilled and poorly paid.

The NILT survey included a list of jobs, ranging from relatively low skills, to manual, and to highly skilled, to explore if the public viewed only certain types of jobs as suitable for someone with autism. We found that most of respondents felt that the majority of the jobs listed may be suitable, although clearly this would depend on the level of relevant skills and level of functioning of the individual (as it would for anyone else) and the level of support available. The majority of the public agreed that the following jobs could be suitable: computer programmer (83%), artist/musician (90%), shelf stacker (85%), sheltered employment (84%), labourer (71%), or waiter/waitress (64%). However, for some highly skilled and socially demanding jobs, there was less agreement amongst respondents as to their suitability, such as doctor (42%), member of parliament or assembly (62%), and lawyer (50%), although many felt that these may be suitable only for high functioning individuals with autism.

We also wanted to find out if businesses would have to worry about customer relations if they employed someone with autism. A supermarket was given as an example of a business that is frequently used by everyone. More than one in ten of the respondents said that they would be more likely to shop in a supermarket that employs someone with autism (12%), while the majority of respondents (86%) said that if a supermarket employed someone with autism, it would make no difference to them. Less than one per cent of people said that they would be less likely to shop in a supermarket that employs someone with autism.

Figure 4: Views on support and intervention for people with autism



The survey explored how people felt about individuals with autism in the community. Most respondents said that they would feel comfortable if an adult with autism moved in next door on their own (83%), married a close relative (80%), or was a work colleague (81%) (Figure 3). Somewhat fewer, yet still nearly three quarters of participants would be comfortable if someone with autism was appointed as their boss (71%). These figures were even higher when we specifically asked the same question about individuals with high functioning autism.

Intervention and support

At present, there is no pharmaceutical treatment for autism. In fact, there is evidence that most drugs that are used to treat irritability, hyper-activity, stereotypy, and aggression in autism either have no evidence base of effectiveness or have harmful side-effects. Other research highlights the fact that most drugs show high incidence of harm and that there is no drug which currently demonstrates effectiveness in treating the social and communicative difficulties associated with autism.

This assessment was reflected in the NILT survey, in that only half of the participants were of the opinion that drug treatments are effective, while the other half of respondents either disagreed, were neutral or unsure (Figure 4). Of course, these data are not evidence of effectiveness: they are

merely evidence of public perception.

There is now sufficient evidence that behavioural interventions based on the scientific discipline of Applied Behaviour Analysis (www.uk-sba.org) are effective and have an established evidence base (National Standards Project, 2009). In fact in the USA, the Office of Personnel Management has classed these kinds of interventions not only as educationally but also as 'medically necessary'.

Parents and caregivers in Northern Ireland, and in the Republic of Ireland expressed the need for behaviour analysis based interventions for their children in the future (Keenan et al., 2010). In line with these findings, participants of NILT survey supported behavioural interventions, with over three quarters (77%) agreeing or strongly agreeing that behavioural interventions are effective.

Although there is no scientific evidence of effectiveness of eclectic interventions (Howard et al. 2005), this was not reflected in public opinion, which thought that other non-drug therapies and supports would be effective. In total, nearly three quarters (74%) thought that there are other non-drug related therapies or supports that are effective interventions.

When parents in Northern Ireland were asked how much support their son or daughter would need to live independently in the future, no one responded by saying

'none'. Rather, views on support needs ranged from occasional through to 24-hour support (Keenan et al. 2010). In line with the views of these carers, very few NILT survey respondents agreed or strongly agreed (4%) with the statement 'people with autism do not need help'.

Education and Health Services

The Autism Act (2011) requires the development of a cross-departmental Autism Strategy. We wanted to find out the general public's awareness with regard to which department they felt was responsible for autism services prior to the development of this strategy so as to be able to assess if the new strategy will have an effect on public perception in this area.

Autism services clearly cover a range of departments. The Department of Health, Social Services and Public Safety is taking the lead in the development of the strategy; however, the Department of Education as well as all other departments obviously have key roles to play. Joined-up thinking and working practices are important for health, social care, education, employment, transport etc., although the level and extent of involvement will vary from individual to individual.

The NILT survey asked the public about whether in their view health services, education services, both or neither, should play a role in helping individuals with autism. Responses were equally distributed between those who thought autism was an educational issue (26%), a health issue (33%), or the involvement of both health and educational services were needed (28%). These responses indicate that the public is unclear about the role of health and education services in supporting individuals with autism, and highlights a need for clearer guidance.

Conclusion

Increasing prevalence of Autism Spectrum Disorders present challenges not only to individuals and families who are directly affected, but also for society as a whole. Services for individuals with autism are costly, but even more costly is the lack of effective service provision. Research reported here showed that the general public is well aware of autism and relatively knowledgeable about the issues faced by individuals and families affected directly.

In fact, we found that three fifths of the population has a family member with autism or know someone with autism. We also found a general acceptance of individuals with autism in the community as evidenced in civil society and customer behaviour. The findings indicate that the general public supports the view that behavioural

interventions offer the best prospect for individuals with autism. Having said this, the general public was unclear about who was responsible for the provision of these services, health, education or both.

In conclusion, this research evidences that the campaign to raise autism awareness

was successful. The public now is aware of autism. The time has come to clearly focus on the need for skills development for quality of life, inclusion, moving out of poverty and into employment through the implementation of evidence-based behavioural interventions and supported by shared responsibility across all Northern Ireland Executive Departments.

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Key points

- There are high levels of public awareness of autism (four out of five respondents are aware of autism, and of these, three out of five have family member or friend/acquaintance with autism).
- Most respondents would feel comfortable if an adult with autism moved in next door on their own (83%), married a close relative (80%), or was a work colleague (81%).
- The majority of respondents (86%) said that if a supermarket employed someone with autism, it would make no difference to them.
- There was considerable support for behavioural interventions (77%), but still some confusion about evidence-based practice.
- The public is unclear about the role of health and education services in supporting individuals with autism, and highlights a need for clearer guidance.

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The **Northern Ireland Life and Times survey** is carried out annually and documents public opinion on a wide range of social issues. In 2012, 1204 adults were interviewed in their own homes. Fieldwork was carried out by Perceptive Insight.

The survey is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day. Check the web site for more information on the survey findings (www.ark.ac.uk/nilt) or call the survey director on 028 9097 3034 with any queries.

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