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## **Awareness and knowledge of autism and autism interventions: A general population survey.**

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**Awareness and knowledge of autism and autism interventions:**

**A general population survey**

*Research on Autism Spectrum Disorders* (accepted, 2013)

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## **Awareness and knowledge of autism and autism interventions:**

### **A general population survey**

#### **Abstract**

Recent figures show that Autism Spectrum Disorder (ASD) affects at least 1 in 88 of the population, yet for years, international public awareness of ASD was limited. Over the past 5-10 years intense efforts have been made to raise autism awareness in the general population in countries such as UK and US. In this paper we report data from a large-scale general population survey (n=1204) in which we assessed autism awareness, knowledge about autism, and perceptions about autism interventions in Northern Ireland. We found high levels of autism awareness, in fact over 80% of the sample were aware of ASD and over 60% of these respondents knew someone with ASD in their own family, circle of friends or work colleagues. Generally, knowledge of strengths and challenges faced by individuals with ASD was relatively accurate. However, perceptions of interventions and service provider responsibilities were vague and uncertain. Results show that local and international autism awareness campaigns have largely been successful and that the focus should shift towards disseminating accurate information regarding intervention and service provider responsibilities.

Key words: autism; autism spectrum disorder; general population; public awareness

Educating the public about Autism Spectrum Disorder (ASD) and thus raising autism awareness has been the focus of large-scale initiatives, laws, and the main *raison d'être* of some large national autism charities in the UK and US. Millions of dollars, pounds and euros have been spent on autism awareness campaigns; the World Autism Awareness Day (WAAD; 2 April) and World Autism Awareness Month (April) have become institutionalised. Huge campaigns such as the *Light it up blue* campaign organised by the charity 'Autism Speaks' are supported by many major cities lighting up blue many major culturally significant landmarks across the world, such as the Sydney Opera House, the Great Buddha in Kobe, Japan, and the Empire State Building. The questions addressed in this paper are, "How effective have autism awareness raising campaigns been?" and "Where should the focus fall next?"

Autism spectrum disorder (ASD) is the term used to describe pervasive developmental disorders diagnosed on the basis of challenges in social communication and restricted interests and repetitive behaviours (American Psychiatric Association [APA], 2013); both of these domains are classified according to severity at three different levels depending on the support requirements of the individual. The diagnosis is reached on the basis of behavioural observations and reports from parents, caregivers, and professionals; currently there are no reliable biological or neurological indicators (Matson, Wilkins, & Gonzalez, 2008).

The prevalence of ASD diagnosis has risen dramatically over the past few decades. While Williams, Higgins and Brayne (2006) reported an estimated prevalence of 1 in 500 between 1979 and 2006, Elsabbagh et al. (2012) estimated the prevalence to be 1 in 161 between 2000-2012. Recent figures published by Centres for Disease Control (CDC) indicate that prevalence rates have risen sharply over the past few years, from 1 in 110 (CDC, 2009) to 1 in 88 (CDC, 2012), and most recently, 1 in 50 amongst children (CDC, 2013). Reasons for the increase in

prevalence are much debated and are likely to include broadening of diagnostic criteria, accuracy of case identification, awareness amongst relevant professionals, as well as actual increase in incidence.

While ASD is a purely behavioural diagnosis, qualitative differences have been found between the brains of individuals with autism and neuro-typically developed individuals (McAlonan et al., 2005). ASD frequently co-occurs with other diagnoses such as epilepsy, mental illness, or intellectual disabilities (MacNeil, Lopes and Minnes 2009). In fact, 22% of individuals with ASD are also diagnosed with epilepsy (Bolton et al., 2011) and many individual with autism present mental health issues such as depression (57%) or anxiety (65%) (Stewart, 2008). In 15-55% of cases, Autism co-occurs with intellectual disability (Elsabbagh et al., 2012). Although well known examples of special or savant abilities exist, such as Daniel Tammet (Johnson2005) and in the movie 'Rain Man', they are relatively infrequent and occur in only 1 out of every 200 individuals with autism (Hermelin, 2001); only about 50% of savants have autism, the other 50% commonly have psychological disorders, brain injuries, or mental illness (Treffert, 2009).

Given the diagnostic criteria, it is not surprising that people affected by autism face challenges in many areas of their lives. Of course, the specific challenges faced vary from individual to individual and educational outcomes for children with autism cover a broad range from above average achievement to marked educational difficulties, although for a number of reasons, children with autism tend to be more likely to have poor educational outcomes (Office for National Statistics [ONS], 2005).

Only 15% of adults with autism are in full time employment (Rosenblatt, 2008) and most individuals with autism experience difficulties with basic practical living skills, such as using public transport (Bancroft, Batten, Lambert and Madders, 2012; Eaves & Ho, 2008). Broach et al. (2003) highlight that waiting at the bus stop, timetable delays, or overcrowded buses cause particular problems for individuals with autism. Clearly these kinds of issues affect quality of life adversely.

Making friends is also challenging as children and young people with autism are more likely to have few or even no friends at all when compared to typically developing children or children with intellectual disabilities (ONS, 2005; Solish et al. 2010). For example, 42% of parents state that their child with autism has no friends. This is in stark contrast to only 1% of parents of typically developing children stating that their child does not have a best friend (ONS, 2005). Low rates of friendship and difficulty making friends have also been reported in adults (Stewart, 2008). Bullying at school can be a major problem for young people with autism (Bancroft et al., 2012). Pupils with high functioning autism or 'Asperger Syndrome' are four times more likely to be bullied than typically developing children (Little, 2002).

Independent living is often restricted and caregivers consider the main barriers to be lack of appropriate housing options as well as safety, personal care, and financial management vulnerability (Broach et al., 2003). Another barrier is the lack of accessible information and advocacy support that could help adults with autism to express their preferences, such as where they would like to live. Indeed, only about one in ten carers of adults with autism say that the adult they care for has received advocacy support (Broach et al., 2003).

Internationally, legislation and campaigns have been introduced to raise the public's awareness of autism, including knowledge of the strengths and challenges associated with autism. Campaigns such as World Autism Awareness Day and month, Autism Speaks' *Light it up blue* campaign, and various autism charity efforts to educate the public have contributed to the fact that specific autism legislation has been introduced in many countries, such as the Combating Autism Act of 2006 in the USA, the Autism Act 2009 in UK, and the Autism Act (NI) 2011 in Northern Ireland.

The Combating Autism Act of 2006 in the USA aimed to 'provide culturally competent information regarding such disabilities and evidence-based interventions for individuals and their families through state and federal programs and community organizations' (Combating Autism Act, 399BBc (1), 2006). Apart from the Centres of Excellence established by the Centers for Disease Control and Prevention (CDC), the Act mandated the establishment of a continuing education curriculum and an Interagency Autism Coordinating Committee.

In the England and Wales, the Autism Act was introduced in 2009, 'to make provision about meeting the needs of adults with autistic spectrum conditions; and for connected purposes' (Autism Act, 2009, p.1). However, despite the Act and the subsequent Autism Strategy, there still are substantial concerns that adequate support is not reaching many adults with autism (National Autistic Society [NAS], 2013).

The devolved Governments in Wales and Scotland have their own 'life-span' Strategies and Action Plans. In Wales, the Action Plan applies to autism services in health, social care and education, with an initial emphasis on raising awareness and 'mapping' autism services to enable the development of effective services in the future (Welsh Assembly Government, 2011). The Scottish Strategy for Autism aims to improve 'Foundations' in mainstream services and diagnoses, the 'Whole Life Journey' through integrated service provision across the

lifespan with effective transition planning, and ‘holistic–personalised approaches’ in regard to partnership working with the voluntary/independent sector (Scottish Government, 2011).

In Northern Ireland the Autism Act became law in 2011 and amended the Disability Discrimination Act 1995 by including in the definition of disability people (both adults and children) 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 lead by the Department of Health, Social Services and Public Safety by mid-2013 with an associated action plan that is to include an autism awareness campaign (Autism Act (NI), 2011).

Despite £millions spent on these campaigns and laws, there was only one medium scale baseline study in Northern Ireland of public awareness prior to the implementation of these action plans to assess the need or indeed the direction of further autism awareness raising campaigns. Stewart (2008) asked 500 people from the Northern Irish general public (aged 16 and over) what they knew about autism and found that most people had heard of autism (87%); and of these, 79% were aware about some of the key aspects of autism. However, most people did not know how common autism was (90%), or had heard of Asperger syndrome (48%), and many held misconceptions such as thinking that people with autism swear inappropriately (48%), were intentionally rude (24%), unable to walk (11%), are mostly children (55%), or had special abilities (62%). A general population survey in the UK based on a sample of over 2000 people (NAS, 2007) found that 92% of people had heard of autism and only 39% of these thought that people with autism have special abilities. Awareness about the core features of autism was relatively low; only 68% were aware that people with autism have difficulty communicating compared to 80% in Stewart’s NI survey (2008). In France, 100% of a sample of 1,000 adults said that they had heard of autism (Durand-Zaleski, Scott, Rouillon, & Leboyer,

2012), although only around two thirds were able to name some of the characteristics which are associated with autism.

The present study expands knowledge of public awareness by assessing a full range of awareness related issues in a large scale population sample in Northern Ireland.

## **Method**

### **Participants**

The sample comprised 1204 adults aged 18 years from households in Northern Ireland. Initially 2,126 people were initially invited to take part in the research, thus this equates to a response rate of 57%. Based on a small effect size achieved from logistic regression (odds ratio = 1.3), this sample size provides a power level of 98%. Unweighted figures show that there was a slightly greater proportion of females (55.3%; CI = 52.5% – 58.1%) in the sample than males (44.7%; CI = 41.9% - 47.5%). The unweighted age breakdown of the sample was as follows: 18-24 years (8.6%; CI = 7.0% – 10.2%); 25-34 years (16.4%; CI = 14.3% – 18.5%); 35-44 years (18.0%; CI = 15.8% – 20.2%); 45-54 years (17.4%; CI = 15.3% – 19.5%); 55-64 years (14.7 %; CI = 12.7% – 16.7%) and 65 years and over (25.0%; CI = 22.6%– 27.4%).

The participant data were weighted to allow for disproportionate household size. The weighted figures showed a similar gender split to the unweighted data for females (54.6%; CI = 51.5% - 57.7%) and males (45.4%; CI = 42.3% - 48.5%). The weighted age profile of the sample was: 18-24 years (11.1%; CI = 9.0% – 13.5%); 25-34 years (15.7%; CI = 13.7% – 18.1%); 35-44 years (18.5%; CI = 16.2% – 21.0%); 45-54 years (18.2%; CI = 15.9% – 20.8%); 55-64 years (15.4%; CI = 13.3% – 17.9%) and 65 years and over (21.1%; CI = 18.8%– 23.5%). The overall

weighted profile of the sample was comparable to that of the Northern Ireland Census 2011 and the 2011/12 Continuous Household Survey. Specific examples of how the NILT 2012 sample compares to the NI Census 2011 and the 2011/12 Continuous Household Survey in terms of composition can be found in the technical report located on the Access Research Knowledge (ARK) website ([www.ark.ac.uk/nilt](http://www.ark.ac.uk/nilt)).

### **Research Tool and Procedure**

The Northern Ireland Life and Times (NILT) survey is an annual cross-sectional survey, recording public attitudes to key social and political issues in Northern Ireland. Founded in 1998, the survey uses a two-stage sampling methodology. First, a systematic random sample of addresses was selected from the Postcode Address File (PAF) database of addresses. Second, one adult was randomly selected from each household. In 2012, a representative sample of 1204 adults aged 18 years or over living in private households across Northern Ireland took part. The response rate was 57%.

NILT has two parts: a main face-to-face interview using Computer Assisted Personal Interviewing (CAPI), and a self-completion section, usually administered using Computer Assisted Self Interviewing (CASI).

In each survey year, the questionnaire is made up of four or five modules, each focusing on a particular topic to reflect current social and public debates. In 2012, the modules focussed on attitudes and knowledge of autism; community relations, minority ethnic groups, migrant workers and asylum seekers; lesbian, gay, bisexual and transgender issues; and political attitudes. In addition, NILT always includes an extensive demographic section. The underlying principle of NILT is public access, and so tables of results, questionnaires, datasets and

technical information are made fully available on the NILT website ([www.ark.ac.uk/nilt](http://www.ark.ac.uk/nilt)) within six months from the end of fieldwork, thus providing timely and free public access; for further information see Devine (2011). The technical information which can be accessed on the ARK website provides the margin of error for sample estimates on key parameters based on 95% confidence intervals (all are within +/- 2.8%). In accordance with the technical guidelines for the survey, the presented figures have been weighted by household size.

## **Results**

The results presented here are a subsection of the autism module NILT survey results. The full list of questions and findings are available elsewhere (NILT, 2012). The vast majority of NILT respondents (82%) stated that they were aware of autism, Autism Spectrum Disorder, or Asperger's Syndrome, while only 16% were unaware and 2% were unsure.

In order to test if particular demographic characteristics are associated with autism awareness, a logistic regression model using employment status, ethnic-minority status, gender, internet use, age and higher education as predictors was performed. Employment status was not a unique predictor of autism awareness and was therefore excluded from the final model. The final model was based on an unweighted total of 1199 participants, 5 participants with missing data were excluded. Ethnic-minority group, gender, internet use, age and higher education predicted whether someone had heard of autism (Table 1). Specifically, the odds of someone from a non-ethnic minority background having heard of autism are 12 times greater than those from an ethnic minority background. Having completed higher education and using the internet (except for work purposes) both trebled the odds of having heard of autism. For females, the odds of having heard of autism were twice those found for males. Age differences in relative odds were also apparent, the 18-24 years age group were significantly less likely to have heard

of autism than the 25-34; 35-44; 55-64; 65+ age groups. Those aged 45-54 years were also more likely to have heard of autism than the 18-24 year olds, and although the difference was non-significant it did approach significance.

The remaining questions in the autism module were asked of those respondents who had heard of autism. Nearly two thirds of these participants (61%) said that they knew someone with autism; of these, 19% had a close relative or other family member with autism, 40% a friend or acquaintance, and 8% had a work colleague with autism; one individual with ASD completed the survey. 39% of the respondents said that they did not know or were unsure if they knew someone with autism.

Insert Table 1 here

For those who did know someone with autism, it was more common to know a child (69%), than an adult (23%) or both adults and children (7%). Participants were also asked to quantify the level of contact that they had with children or adults affected by autism; over one fifth stated that they had a lot of contact (22%) and around four in ten respondents had little contact (41%).

Amongst those with an awareness of autism, only one fifth (20%) had heard of the Autism Act NI 2011.

Logistic regression was used to assess the factors associated with being aware of autism legislation; this analysis was based on 948 participants who had heard of autism, excluding 22 participants who did not indicate the level of contact they had experienced with individuals

affected by autism (unweighted figures). The following demographic variables were initially included in the logistic regression model: age, employment status, gender, contact level with people affected by autism, higher education, and internet use. After running the model, predictors that were non significant were removed, and this process was repeated until the most parsimonious significant model was obtained.

Statistical analysis indicated that individuals who had a lot of contact with individuals with autism had odds three times greater than those who had experienced a little contact and 6.4 times greater than those who had experienced no contact, of having heard of the Autism Act (Table 2). For females, the odds of having heard of autism legislation were 1.5 times relative to those for males. Additionally, for those who had completed higher education the odds of being aware of the Autism Act were 2.5 times greater than those who had not completed higher education. However, as Table 2 reveals, levels of awareness amongst those who had a lot of contact, were female, or had a higher education were still low.

Insert Table 2 here

### **Strengths and Challenges**

Each participant was asked to list the main strengths and challenges 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. The unweighted number of times that each word was mentioned by the participants is displayed in brackets after each word. 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 the strengths that individuals with autism possess. Just over one third (N=326) of respondents did not answer this question.

Insert Figure 1 here

When asked to name the challenges 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 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.

Insert Figure 2 here

### **Estimated prevalence of autism**

Participants completing the NILT survey were asked to pick which of three figures was the closest approximation of the prevalence rate for autism; one estimate was in line with current research (1 in 100), while the other two underestimated the prevalence of autism (1 in 1,000; 1 in 10,000). Most participants in the study who had heard of autism, either underestimated

prevalence to be 1 in 1,000 (37%) or 1 in 10,000 (10%) or said that they did not know how prevalent it was (15%). Consistent with current prevalence estimates, 38% of respondents thought that autism was as prevalent as 1 in 100.

In order to examine the association between demographic variables and knowledge of autism prevalence a logistic regression was performed. A total of 958 participants gave an answer to the prevalence question; however, as 13 of these participants had missing data on at least one of the predictor variables the analysis was restricted to 945 participants (unweighted figures). The predictor variables that were entered into the initial logistic regression model were age; employment status; gender; contact level with people affected by autism; higher education; and internet use. The final model (Table 3) retained only the predictors that were significant.

This analysis showed that contact level with someone affected by autism is associated with knowledge of autism prevalence. Specifically, the odds of knowing the approximate prevalence of autism for someone with a high level of contact were 1.6 times those of someone with a little contact, and 2.3 times those of someone with no contact. Females had odds of knowing the prevalence of autism that were 1.7 times greater than those for males. There is also a relationship between age group and knowledge of autism prevalence. Compared to those aged 65+, 18-24 year olds had odds of being knowledgeable about autism prevalence that were 2.5 times greater. A greater proportion of 18-24 year olds (42%) were aware of autism prevalence than those aged 55-64 (32%), and this difference approached significance. Similar to the analysis for awareness of autism legislation, amongst those who had a lot of contact with individuals affected by autism, were female, or were aged 18-24 knowledge of autism prevalence was still low.

Insert Table 3 here

### **Features of Autism**

Only 13% of respondents thought that autism was definitely a brain disorder (Table 4), although a sizable proportion did think that it was probably a brain disorder (44%). The remaining respondents (43%) either thought that autism was probably/definitely not a brain disorder or were unsure.

Only 5% of participants believed that individuals with autism definitely have a mental illness, while at the other extreme 28% felt that someone with autism definitely did not have mental health problems (Table 4). Most participants were less definitive, stating mental health problems ‘probably’ (30%), or ‘probably did not’ occur alongside autism, (25%), or that they were unsure (12%).

Just over one quarter (26%) of the NILT sample believed that autism is definitely characterised by atypical behaviours (Table 4). One half of respondents (49%) thought that individuals affected by autism probably had a behavioural problem.

When asked if autism is a learning disability, 30% said ‘definitely’ and 5% definitely not (Table 4). Most participants felt that there was a possibility that someone with autism would have a learning disability. Specifically, in response to the statement ‘someone with autism has a learning disability’ half the sample said ‘probably’ and 7% ‘probably not’.

The vast majority of respondents in the NILT sample thought that individuals with autism either definitely had or probably had (84%) special abilities (Table 4). In contrast, only 4% said that someone with autism was unlikely to have special abilities.

Insert Table 4 here

### **Role of Health and Education**

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%).

### **Discussion**

Given increasing prevalence rates of ASD it is important that the general population is aware of it and is able to respond responsibly to the associated strengths and challenges. We included questions about ASD into a general population survey (NILT), prior to the implementation of a local ASD strategy. The results of the NILT autism module show that the general public is well aware of autism and relatively knowledgeable about the issues faced by individuals and families affected directly. However, there was a lack of clarity about responsibility for effective service delivery.

The present study found that 82% of the public have heard of autism, a figure consistent with that reported in an earlier autism awareness survey (Stewart, 2008). Arguably, this level of autism awareness can be considered as high, despite being 10 percentage points below that found in the UK (NAS, 2007). The high level of awareness reported in the present study may

be partly explained by the finding that nearly two thirds of the sample had a family member with autism or knew someone with autism in their wider social circle. This finding is not surprising given the high estimated prevalence of autism (1:88) and the fact that most people probably know more than 88 people; the chances of knowing someone on the autism spectrum is relatively high. Durand-Zaleski et al. (2012) found that in France 100% of adults were aware of autism. However, this survey used online methods meaning that the sample were computer literate and used the internet. As the present study found an association between internet use and autism awareness, it is likely that the study by Durand-Zaleski et al. (2012) overestimated autism awareness amongst the French public.

Autism awareness did vary across demographic characteristics. Specifically, factors associated with lower autism awareness included being male, not completing higher education, being a young adult (aged 18-24), not using the internet, and being from an ethnic minority background.

The lowest level of awareness was found amongst those from an ethnic minority background, where less than half had heard of autism. Of course, it is possible that the term 'autism' may not translate well for anyone who does not speak English as a first language, and that this figure could underestimate the actual level of autism awareness amongst those from an ethnic minority background. Excluding those from an ethnic minority background, who represented a relatively small proportion of the sample, when autism awareness was broken down by demographic subgroups autism awareness levels were at least 75%, suggesting awareness levels are good amongst different sections of the public and that while autism awareness could be raised by targeting specific groups (e.g., males, young adults), many people would be

targeted unnecessarily. In addition, targeting specific subgroups could mean that some people who could benefit from better autism awareness would be excluded.

While awareness of autism was good, only one fifth of the sample was aware of local autism specific legislation. Awareness of this legislation was higher amongst those who had a lot of contact with people affected by autism, compared to those with little or no contact. Awareness was also higher amongst females than males and for those who had completed higher education relative to those who had not. Yet, for none of these demographic subgroups was awareness of the Autism legislation above 50%, suggesting that awareness-raising of this legislation would be beneficial for most members of the public, regardless of their demographics. Arguably, the Autism Act (NI) (2011) may not yet have been brought to the public's attention as much as its sister act in England and Wales, or similar legislation in the US. It is therefore possible that different levels of awareness of local legislation would be found in England, Wales and the US.

Using a quantitative approach, Stewart (2008) and NAS (2007) found that the most people in the UK and vast majority in Northern Ireland recognised that individuals with autism face challenges with communication, dealing with changes in routine, making sense of the world, difficulty making friends, and obsessive behaviours. In contrast, the present study adopted a qualitative approach by allowing people to spontaneously name the strengths as well as the challenges that they associated with autism, thus not restricting or pre-empting their responses. When asked about the strengths associated with autism, the majority of the participants mentioned something positive such as being intelligent, creative, loving or determined. The academic strengths listed would, of course, not apply to everyone who has autism, just as they

would not apply to everyone in the general population. Nevertheless, it is encouraging to see that people had such positive views on individuals with autism.

The NILT survey participants also named a range of challenges, which overlapped with but also extended beyond the range of challenges that the public recognised in previous surveys (NAS, 2007; Stewart, 2008). The range of challenges (expressed freely to an open ended question) covered many of the core features of autism as well as challenges in other areas of life which have been identified in the literature such as gaining employment (Rosenblatt, 2008), being independent (Broach et al., 2003), learning (Elsabbagh et al., 2012). Some participants rightly pointed out that individuals with autism are likely to vary in terms of the difficulties that they experience. Overall, issues such as difficulty finding employment, mental health problems, dependency on parents, and individual differences in difficulties faced were mentioned infrequently by the respondents, and this is likely to reflect the lack of focus on these issues by the UK media (Huws & Jones, 2010).

While in the past autism was considered relatively uncommon, recent studies evidenced increasing prevalence rates up to 1 in 88 for all age groups (CDC, 2012) and 1:50 children (CDC, 2013). Our survey revealed that 38% of the public were aware of this increase, however, a similar proportion of the participants estimated the prevalence to be more in line with figures reported over 10 years ago, when autism prevalence was estimated to be approximately 1 in 900/1000 (Croen, Grether, Hoogstrate & Selvin, 2002). The remaining participants were either unsure about prevalence or thought that autism occurred less than 1 in 10,000, i.e., figures reported in the 1970s (Frombonne, 1999). These findings indicated that many people were not aware of how common autism is, despite the fact that they actually knew someone with ASD. Indeed, while level of contact with someone affected by autism was associated with knowledge

of autism prevalence, only half of those who had a lot of contact with someone with autism were aware of how prevalent autism is. More than two fifths of younger adults who had heard of autism (i.e. 18-24 years) know how prevalent autism is, compared to around one fifth of those aged 65 plus. This finding may be partly due to the higher prevalence of autism in younger age groups (e.g. CDC, 2013), i.e. there is likely to be a higher prevalence of autism amongst the peers of 18-24 year olds than amongst those of 65+ year olds. Consistent with the analysis for awareness of autism, and awareness of autism legislation, females were more likely than males to be aware of the prevalence of autism. The notion of 'it only happens to me' is not unfamiliar in psychology especially in situations of crisis. It is the cornerstone of self-help and support groups, where people in similar situations meet and realise that indeed 'it' does not only happen to them, 'it' happens to others too. This realisation is often considered helpful and allows for learning from others through modelling and imitation (Lindsay, Moore, Anderson & Dillenburger 2013).

Consistent with Stewart (2008), the majority of our participants felt that someone with autism would have special abilities, even though in fact only 1 in 200 individuals with autism does (Hermelin, 2001). On the one hand, it is possible that participants may have adopted a broader definition of special ability than that of Hermelin (2001), but it also likely that people have been influenced by the portrayal of individuals with autism in the media (e.g. the film *Rain Man*).

While autism is a neurodevelopmental disorder (e.g., McAlonan et al., 2002, 2005), only 57% of respondents believed that autism was a brain disorder. More than four in ten participants did not think that there was a link between the brain and autism. Awareness that autism is not a mental illness was high, with only 5% saying that individuals with autism definitely have a

mental illness, however there was recognition mental health problems co-occur frequently and these views are consistent with the research literature (MacNeil et al., 2009). The rate of co-occurring learning difficulties is not well established and estimates vary between 15-55% (Elsabbagh et al., 2012). This disparity was reflected in the public perception. Yet, the vast majority of respondents were aware that individuals with autism can display challenging behaviours.

Legislation such as the Autism Act (NI) 2011 clarifies which departments are responsible for developing the new Autism Strategy. The Autism Act (NI) 2011 identifies the Department of Health and Social Services as taking the lead in strategy development, but also specifies a role for other departments. For example, the Department of Education plays a key role in strategic development of educational services. Clearly, joined-up working practices are important for health, social care, education, employment, transport, and others. We found that the public was quite unclear about the role of the key departments highlighting the need for more clarity and leadership when in devising new strategies and policies that raise awareness of the departmental roles. For example, the new Autism Strategy to be published in 2013 in Northern Ireland and the associated action plans offer a unique opportunity to provide guidance with regard to the roles that health, education and the other areas of government play.

In sum, the NILT survey autism module offers a baseline against which the impact of new autism legislation, policies, and strategies can be measured. The survey revealed that by-and-large the public is aware of autism and its key features. Nearly two thirds of participants knew someone on the autism spectrum. While there was a tendency to overestimate the occurrence of special talents, overall there were good levels of awareness and knowledge of autism. These findings indicate that local and international efforts to improve autism awareness amongst the

public have been successful. While there is always more room for detailed public education about autism, findings reported here show that the time has come to shift the focus from mere awareness raising campaigns to a more sophisticated approach that delivers clarity with regard to intervention, accountability and responsibility.

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Note.  $R^2 = .12$  (Cox & Snell)  $.19$  (Nagelkerke). Model  $\chi^2 (9) = 146.19$ ,  $p < .001$ , OR= odds ratio; CI 95% = confidence interval of 95%.

**Table 2.** Summary of logistic regression for variables predicting autism legislation awareness

	Heard of Autism Act		b	p	OR	95% CI	
	% Yes (N)	% No (N)					
Constant			-1.98				
Gender							
Male	15.56 (66)	84.44 (356)	.40	.026	1.49	1.05 2.11	–
Female (reference)	23.53 (133)	76.47 (434)					
Higher education							
Yes (reference)	31.90 (101)	68.10 (216)					
No	14.58 (98)	85.42 (574)	.93	< .001	2.53	1.81 3.55	–
Contact							
A lot (reference)	41.37 (89)	58.63 (126)					
A little	19.42 (77)	80.58 (320)	-1.10	< .001	0.33	0.23 0.49	–
None	8.96 (30)	91.04 (306)	-1.85	< .001	0.16	0.10 0.25	–
Don't know	17.24 (3)	82.76 (13)	-1.09	.115	0.34	0.09 1.30	–

Note.  $R^2 = .11$  (Cox & Snell) .18 (Nagelkerke). Model  $\chi^2 (5) = 116.02$ ,  $p < .001$ , OR= odds ratio; CI 95% = confidence interval of 95%.

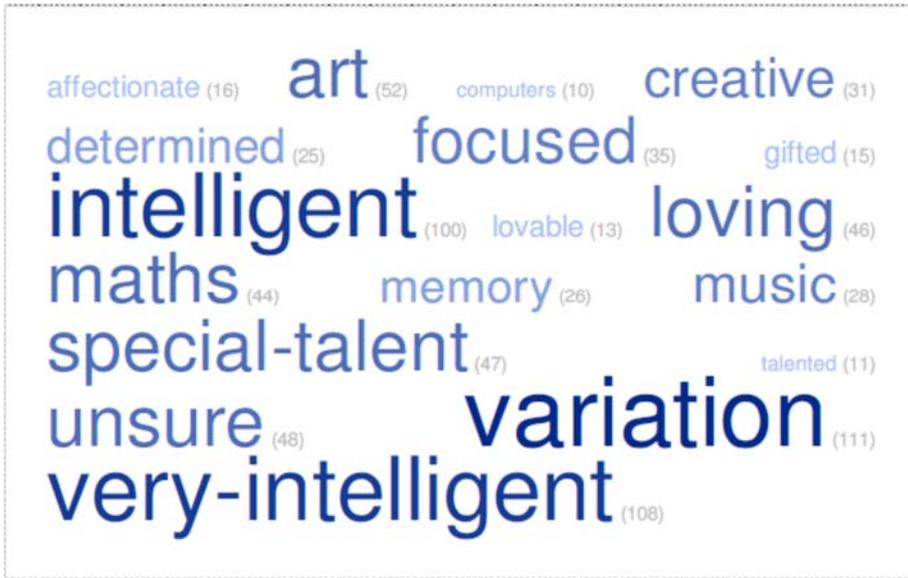
**Table 3.** Summary of logistic regression for variables predicting awareness of autism prevalence

	Aware of autism prevalence		b	p	OR	95% CI
	% Yes (N)	% No (N)				
Constant			-0.43			
<b>Gender</b>						
Male	30.24 (126)	69.76 (291)	.53	<.001	1.70	1.29 – 2.25
Female (reference)	44.16 (246)	55.84 (311)				
<b>Contact</b>						
A lot (reference)	51.27 (110)	48.73 (105)				
A little	38.29 (152)	61.71 (245)	.48	.006	1.62	1.15 – 2.29
None	29.53 (99)	70.47 (236)	.81	<.001	2.25	1.56 – 3.25
Don't know	37.93 (6)	62.07 (10)	.48	.383	1.62	0.55 – 4.79
<b>Age</b>						
18-24 years (reference)	42.31 (42)	57.69 (57)				
25-34 years	44.06 (69)	55.94 (87)	.01	.960	1.01	0.60 – 1.71
35-44 years	46.13 (88)	53.87 (103)	-.11	.672	0.90	0.54 – 1.48
45-54 years	45.43 (81)	54.57 (98)	-.00	.997	1.00	0.60 – 1.66
55-64 years	31.85 (51)	68.15 (109)	.51	.059	1.67	0.98 – 2.84
65+ years	21.87 (41)	78.13 (147)	.93	.001	2.52	1.47 – 4.32

Note.  $R^2 = .072$  (Cox & Snell)  $.098$  (Nagelkerke). Model  $\chi^2(9) = 72.22$ ,  $p < .001$ , OR= odds ratio; CI 95% = confidence interval of 95%.

**Table 4:** Views on the features of autism

	Definitely	Probably	Probably not	Definitely not	Don't know
Brain disorder	12.66%	44.46%	15.98%	12.21%	14.69%
Mental illness	4.56%	29.99%	25.21%	28.02%	12.21%
Behavioural problem	25.72%	49.47%	10.35%	6.75%	7.71%
Learning disability	30.12%	50.39%	6.64%	5.24%	7.60%
Special abilities	43.27%	40.62%	3.83%	0.56%	11.72%



**Figure 1:** Word Cloud of the strengths which people associate with autism



**Figure 2:** Word Cloud of the challenges which people associate with autism

## Highlights for review

- For years, international public awareness of ASD was limited.
- Intense efforts have been made to raise autism awareness in the general population.
- Data reported from a large-scale general NI population survey of autism knowledge/attitudes.
- High levels of autism awareness found: over 80% aware of ASD; over 60% know someone with ASD.
- Good level of knowledge of strengths and challenges faced by individuals with ASD.
- Interventions and service provider responsibilities were vague and uncertain.
- Local and international autism awareness campaigns have been successful.
- Focus now on disseminating accurate information about intervention and service provider roles.

