



Children and young people's awareness, knowledge, and attitudes towards autism in Northern Ireland

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Introduction

Autism Spectrum Disorder (ASD) is diagnosed on the basis of pervasive behavioural difficulties in social communication and restricted, repetitive behaviours that are observed from a very early age (APA, 2013); co-occurring intellectual disabilities affect 50-75% of the individuals diagnosed with ASD (Matson & Shoemaker, 2009). The estimated prevalence rate of autism across all age groups is approximately 1 in every 88 (CDC, 2015), while in Northern Ireland, 2% of school children are known to be on the autism spectrum (DHSSPS, 2014). However, this may be an underestimation of prevalence as parents of 3.5% of 11-year-old children in the UK (including NI) who took part in the Millennium Cohort Study were told their child had ASD (Dillenburger, Jordan, McKerr, & Keenan, 2015). Boys seem to be diagnosed more frequently than girls, although it is not clear why this is the case. In Northern Ireland, the Autism Act (Northern Ireland) (2011), the Autism Strategy (2013-2020) and Action Plan (2013-2016) (Northern Ireland Executive, 2014) set a legal parameter of service provision.

While the inclusion of an autism module in the Northern Ireland Life and Times (NILT; n=1204) survey revealed high levels of autism awareness (82%; Dillenburger, Jordan, McKerr, Devine,

& Keenan, 2013) and relatively positive attitudes about autism amongst adults in Northern Ireland (Dillenburger, McKerr, Jordan, Devine, & Keenan, 2015), little is known about children and young people's awareness, attitudes, and knowledge about autism, even though children and young people are very likely to meet peers with autism in increasingly inclusive classrooms.

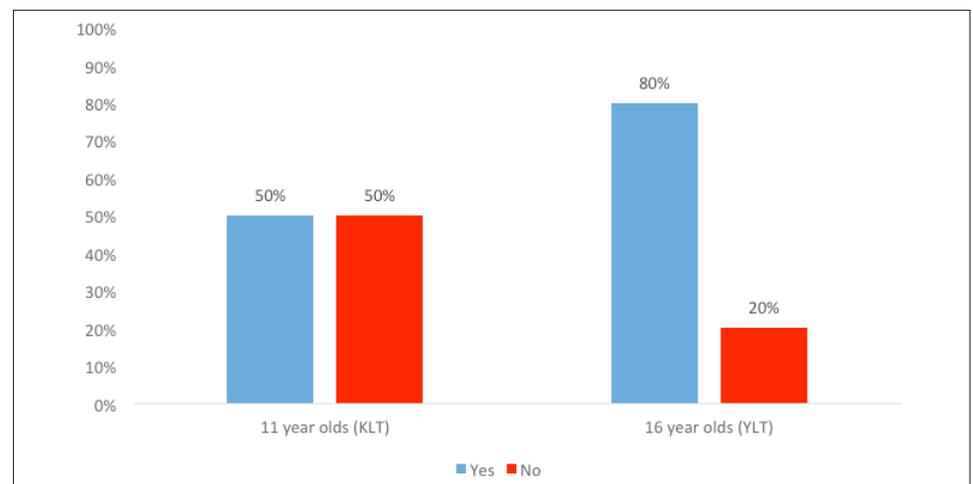
This research up-date presents data from the 2014 autism modules that were included in the Kids Life and Times (KLT) Survey (total responses n=2319) and the Young Life and Times (YLT) Survey (total responses n=1034) to measure awareness, knowledge, and attitudes, towards autism in Northern Ireland.

Autism prevalence in these randomly selected samples was similar to that reported in the secondary data analysis of the Millennium Cohort Study (Dillenburger, Jordan, et al., 2015); 2.7% of the 11-year-old KLT participants and 3.1% of the 16-year-old YLT participants stated that they had autism themselves.

Awareness and knowledge of autism

Only half of 11-year-olds (50%) who took part in the KLT Survey thought that they knew what autism was, while most of the 16-year-olds who took part in the YLT Survey were aware of autism (80%; Figure 1).

Figure 1: Proportion of 11-year olds and 16-year-olds who say they know what autism is.



Notes: KLT (yes = 1158, no=1161) YLT (yes=816, no=198).

Figure 2 shows that the words most frequently used to describe autism by 11-year-old KLT participants (total responses n=982) painted a relatively accurate picture of the condition.

Figure 3 shows equally accurate knowledge about autism in 16-year-old YLT participants (total responses n=780). In each word cloud, the frequency with which a word was mentioned is displayed in brackets after the word and the more frequently a word was mentioned the larger is its physical size.

There was some degree of overlap between YLT and KLT respondents in terms of the use of general descriptors such as 'disability' and 'condition'. However, not surprisingly, 16-year-olds had a more sophisticated knowledge and understanding of autism than 11-year-olds and went beyond the use of general descriptors to name the defining features of autism including 'behaviour', 'communication', and 'social' difficulties. In fact, their level of understanding was reminiscent of that of the adult respondents in the NILT 2012 survey (Dillenburger et al., 2013)

Personal contact with peers with autism

According to the NILT 2012 survey, half of NI adults (50%) knew someone who had autism personally (Dillenburger et al., 2013). The YLT results showed that an even greater proportion of 16-year-olds (72%) reported knowing someone with autism, whereas the KLT results show that the younger children were less likely know someone with autism (43%).

Compared to 11-year-old KLT respondents, a greater proportion of 16-year-old YLT respondents reported having a relative (12% vs 16%), a friend (14% vs 24%), a school-mate (14% vs 30%), or a neighbour (7% vs 17%) who has autism.

Figure 2: Knowledge of autism of 11-year-olds in Northern Ireland



Figure 3: Knowledge of autism of 16-year-olds in Northern Ireland



Attitudes towards inclusion of individuals with autism

Increasingly children with disabilities, e.g., autism, are included in education in mainstream schools (UNCRPD, 2006). For inclusion to be successful, both positive peer attitudes and appropriate additional supports are important. Table 1 illustrates peer attitudes of both 11-year-olds and 16-year-olds towards inclusion of children with autism, e.g., moving into their neighbourhood and school. It also illustrates attitudes towards the need for additional supports.

The YLT and KLT surveys showed that 16-year-olds were more likely than 11-year-olds to report feeling comfortable if a family who had a child with autism moved in next door to them (82% vs 40%) or if a child with autism was included in their class at school/college (77% vs 45%). These figures contrast somewhat with adult figures reported earlier that showed that over 90% of adults in NI felt comfortable with these kinds of inclusive practices (Dillenburger, McKerr, et al., 2015), although the delivery of additional supports in the classroom was more widely supported by 11- and 16-year-olds (81% – 90%).

Table 1: Attitudes towards autism amongst 11- and 16-year-old peers

| Issue | Response options: | 11 year olds (KLT) | 16 year olds (YLT) |
|---|--|--------------------|--------------------|
| Attitudes towards a family who had child with autism moving in next door | Comfortable | 927 (40%) | 844 (82%) |
| | It depends | 787 (34%) | 131 (13%) |
| | Uncomfortable | 154 (7%) | 8 (1%) |
| | Don't know | 425 (19%) | 51 (5%) |
| Attitudes towards a young child with autism being in their class at school/college | Comfortable | 1032 (45%) | 795 (77%) |
| | It depends | 638 (28%) | 166 (16%) |
| | Uncomfortable | 174 (8%) | 21 (2%) |
| | Don't know | 441 (19%) | 52 (5%) |
| Attitudes towards someone in their class getting extra help from a teacher or classroom assistant | That's not fair, we should all be treated the same | 178 (8%) | 24 (2%) |
| | A bit jealous because I might need help too | 88 (4%) | 40 (4%) |
| | That's ok, because they need extra help | 1793 (81%) | 926 (90%) |
| | Other/Don't know | 154 (7%) | 34 (3%) |

Bullying

Children and young people with autism frequently experience bullying and victimisation that can have adverse effects on their academic performance (Cappadocia, Weiss, & Pepler, 2012); pupils with high functioning autism or Asperger syndrome are more likely than their peers to report having been bullied (Bancroft, Batten, Lambert, & Madders, 2012) and to be subjected to verbal aggression from peers (Humphrey & Symes, 2011). age, and gender matched comparison groups of 35 adolescents with dyslexia and 38 with no identified special educational needs (the ASD and dyslexia groups were also matched on SEN provision.

One in six of the children and young people (17% of the 11-year olds and 18% of the 16-year-olds) said that they had seen a child or young person with autism being bullied. The most common response to this observation was to tell the bully to stop (55%), telling a staff member (32%), telling another young

person (21%), or telling someone in the person's family (14%). Less than one in ten respondents (9%) said that they did nothing at all to stop the bully. Very few of the participants (2% of the 11-year olds and 1% of the 16-year-olds) said that they themselves had bullied someone with autism.

Conclusion

Recent research showed that the adult population in Northern Ireland generally is well aware and knowledgeable about the issues faced by individuals and families. This present research update reported, for the first time, on autism awareness, attitudes, and knowledge of children and young people.

Results indicate that self-reported prevalence figures (2.7% for 11-year-olds and 3.1% for 16-year-olds) substantially exceeded official figures of prevalence amongst school age children (2%; (DHSSPS, 2014) and concurred with the

evidence that prevalence rates are rising (Dillenburger, Jordan, et al., 2015).

Not surprisingly, 16- year-olds had a more sophisticated understanding of autism than 11-year-olds. Both groups associated autism more with challenges rather than with strengths. It was worrying that one in six of the respondents had seen a peer with autism being bullied; however, it is encouraging to know that over half of the teenagers said they had intervened to try and stop the bullies.

Research reported here adds to knowledge on school inclusion in that it provided evidence that children and young people are aware of autism and happy to be educated inclusively with their peers with autism and were in favour of educational supports, where needed. These findings bode well for the use of peer-mediated interventions (PMI) that involve typically developing peers as 'facilitators' in the classroom (Zhang & Wheeler, 2011). The policy of not educating peers about the autism diagnosis of their classmates (Doyle, 2003) should be reviewed in light of these findings.

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Key points

- The number of 16-year-olds (3.1%) and 11-year-olds (2.7%) who self-report autism exceeds official prevalence figures (2%);
- Awareness of autism among teenagers is comparable to autism awareness in the general population (80% vs 82%), while not unexpectedly, autism awareness is lower among younger children (50%);
- Children and young people are aware of the challenges posed by an autism diagnosis;
- Children and young people approve of peers with autism receiving additional educational support where needed; and take action to prevent bullying.

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