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## Knowledge Exchange Seminar Series (KESS)

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### Preventing poverty and social exclusion for those affected by autism and their families

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#### Background

Autism rates in Northern Ireland are rising by 0.2% annually and now stand at 2.3% in the school population (Waugh, 2016). The annual cost to society with respect to autism services and lost economic opportunities for individuals and/or their carers is £34 billion in the UK, more than cancer, strokes, and heart disease combined; 36% of this cost is for adult services (Buescher, Cidav, Knapp, & Mandell, 2014). Although the NI government has invested heavily in autism, waiting lists for assessment are rising, overall services are still not meeting the needs of those directly affected by autism and their families, and there is a feeling that the money is not always spent wisely.

#### Outline of briefing paper

A major study was funded by OFMDFM<sup>2</sup> (2012-2016) to explore poverty and social exclusion of individuals affected by autism and their families, and to make policy and practice recommendations. There were 4 phases of this study, with the working title: BASE project (Benchmarking Autism Services Efficacy):

- (1) A thorough literature review;
- (2) An adult population survey of autism awareness and attitudes in Northern Ireland;
- (3) A comprehensive secondary data analysis of existing data banks; and
- (4) Detailed qualitative data analysis from surveys and interviews with professionals, individuals with autism and parent/carers of individuals with autism.

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# Knowledge Exchange Seminar Series 2016-17

This briefing paper outlines the major findings from each phase. The summary report (BASE Project Report Volume 5; Dillenburger, McKerr, & Jordan, 2015) is available to download free from: <https://www.executiveoffice-ni.gov.uk/sites/default/files/publications/execoffice/BASE%20Vol.5.%20Final%20report.pdf>

Full reports from each research phase (BASE Project, 2016) are available to download free from: <http://www.qub.ac.uk/research-centres/CentreforBehaviourAnalysis/Research/BenchmarkingAutismServiceEfficacyBASE/>

## What is autism?

The two main diagnostic systems used by clinicians, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) and the International Classification of Diseases (ICD-10; WHO, 1992), define Autism Spectrum Disorder (ASD) as a pervasive developmental condition characterised by specific atypical behaviours in social communication and repetitive, restrictive behaviours. The severity which with these behaviours affect the person's behaviour vary from individual to individual; some examples are shown in Table 1. To date no medical diagnostic tests are available (e.g. no blood tests or MRI scans) and the diagnosis is determined on the basis of behavioural observations by clinicians or reports from parent/ carers, teachers, and other professionals<sup>3</sup>. The diagnosis of Asperger's Syndrome is no longer used as a separate category in DSM-5 (APA, 2013). Although internationally, most clinicians and researcher use the DSM-5, or its predecessor, the DSM-IV, most diagnosticians in Northern Ireland use the ICD-10 (WHO, 1992).

**Table 1: Examples of behaviours observed that may lead to autism diagnosis**

<i>Social interaction and Communication</i>	<i>Restricted and repetitive behaviours</i>
Difficulty with initiating or sustaining a conversation; Difficulty reading facial expressions accurately; Difficulties building and maintaining peer relations; Developmental delay in language ability.	Repetitive behaviours; Restricted interests; in some cases, special abilities, e.g., very good memory of very specific facts; Inflexible adherence to routines; Sensory issues, e.g., sensory overload or distortion; Difficulties with perspective taking.

## Autism prevalence

The secondary data analysis of the School census confirmed Department of Health figures that in Northern Ireland, 2.3% of school children have autism, however, adult autism prevalence rates could not be established as these data are not collated in any existing data sets. The secondary data analysis of the Millennium Cohort study, a UK-wide study of families of children born in the year 2000 (n=18,522; Fitzsimmons, 2000) established that parents of 3.5% of 11-year-old children were told that their children have autism (Dillenburger, Jordan, & McKerr, 2014).

In Northern Ireland, these data were confirmed by the 2014 Kids Life and Times Survey (KLT; n=2319; Dillenburger, Lloyd, McKerr, & Jordan, 2015) and the 2014 Young Life and Times Survey (YLT; n=1034; Dillenburger, Schubolz, McKerr, & Jordan, 2015), that showed that 2.7% of the children (10-11 years-of-age) and 3.1% of young people (16 years-of-age) identified themselves as being on the autism spectrum (Dillenburger, McKerr, & Jordan, 2015).

<sup>3</sup> The current exception is the identification of autism associated with Fragile X Syndrome, a genetic developmental condition that can be diagnosed using a specific polymerase chain reaction [PCR] test (National Human Genome Research Institute, 2016); for further details about Fragile X Syndrome, see <https://www.genome.gov/19518828/learning-about-fragile-x-syndrome/>

### Are individuals with autism and their families amongst ‘the most vulnerable’ people in Northern Ireland?

Figures from Department of Work and Pensions (Carr, Councill, Higgs, & Singh, 2014) show that when compared with families who have no disabled member, families that include a disabled family member are more likely to live in relative poverty and have low incomes than other families (22% compared to 15%). There has been an upward trend in terms of relative poverty of families affected by disabilities over the past five years, and although these figures do not specify the disability, they include the growing number of families affected by autism.

The cost of autism in the UK is estimated to be about £0.9-1.5 million across a single lifetime (depending on how much support the individual requires) with the total annual cost estimated to be £34 billion per year and most of this is due to lifetime care costs and unemployment of individuals with autism and their parents (Buescher, Cidav, Knapp, & Mandell, 2014).

The BASE Project established that in Northern Ireland almost half of parents of children with autism adjusted their lifestyle either by leaving employment (20%), reducing their working hours or limiting their occupation choices, because of their care giving responsibilities. The findings confirmed earlier studies (e.g., (Employers For Childcare, 2016) that good quality daycare for children with autism is very difficult to find (Dillenburger & McKerr, 2014). Additional cost for child-minders were identified, due to reduced number of places a childminder can offer if they included children with disabilities. Where children exhibit challenging behaviours, finding adequate childcare is next to impossible.

The secondary data analysis (BASE Volume 3; Dillenburger, Jordan, & McKerr, 2014) showed that parents who were in employment were on average £28-£64 worse off per week than other families, while experiencing expenses between 3-6 times higher (Contact a Family, 2012).

Accurate employment figures for adults with autism are not available in Northern Ireland, however, it is safe to assume that they are in line with findings from the National Autistic Society that established employment of adults with autism as low as 15% (Rosenblatt, 2008).

### Why are individuals with autism and their families amongst ‘the most vulnerable’ people in Northern Ireland?

The identification of factors that contribute to inequality is difficult. However, it is clear that the establishment of a diagnosis is a likely starting point to identify individuals that are vulnerable. Yet, the BASE Project established that, in Northern Ireland, the diagnosis process is often protracted and delayed for both children and adults; the ‘watch-and-wait’ approach in some Trusts means autism diagnosis for children can take more than 2 years (BASE Volume 3; cf., Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), while adult diagnostic and support services remain severely underdeveloped (BASE Volume 4) Out of the five regional Health and Social Care Trusts, to date only the Northern and Belfast Trusts have committed to providing an adult service; they have done so by engaging in partnership with other social care providers and service users, although adult autism funding continues to be limited (Dillenburger & McKerr, 2015)

In relation to international best practice, early intensive applied behaviour analysis-based interventions are established as ‘gold standard’ (NAC, 2015; Perry & Condillac, 2003; Surgeon General, 1999). These kinds of interventions are considered ‘treatment as usual’ in USA (Autism Speaks, 2014) and Canada (PPM-140, 2007) and there is evidence that they are cost-effective (Jacobson, Mulick, & Green, 1998; Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006; Peters-Scheffer, Didden, Korzilius, & Matson, 2012) and statistically significantly related to optimal outcomes (Orinstein et al., 2014; Troyb et al., 2014).

However, these kinds of interventions are not available in Northern Ireland’s statutory sector (BASE Volume 1), in fact, families are often dissuaded from their use (Howlin, 2013; Hughes, 2008). Parents, searching the internet or learning about these interventions by word of mouth are oftentimes better informed than professionals (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Fennell & Dillenburger, 2016). Thus, although applied behaviour analysis (ABA) based interventions are provided in Northern Ireland by an increasing number of qualified Board Certified Behaviour Analysts (BACB, 2015), families have to access them privately, either through a voluntary sector/not for profit organisations or from independent practitioners, which comes at a cost to parents.

Absence of effective interventions means behaviours that interfere with constructive learning (both socially and academically) are not addressed. During the interviews, parents reported that they felt their children’s difficulties were not adequately addressed in

by health or education professionals (BASE Volume 4). For example, the secondary data analysis (BASE Volume 3) indicated that children with autism miss school between 8 and 13 days more than other children; some 20% of children were frequently excluded from school and a similar number were bullied. Unsurprisingly therefore, educational attainment is lower for children with autism (some 20-40 percentage points lower than for other children) (Ambitious about Autism, 2014; Dillenburger, Jordan, & McKerr, 2016).

In economic terms, families affected by autism have a higher incidence of unemployment (up to 20% higher than other families), and many parents of children with autism give up full-time employment to care for their child (BASE Volume 3). As a result, family income can be up to 12% lower in families affected by autism (BASE Volume 3). These families are also more likely to live in deprived areas (6 percentage points more than other families) (BASE Volume 3).

The Autism Act (2011) and the subsequent Autism Strategy (2013-2020) and Action Plan (2013-2016) aimed to address inequalities. However, BASE Project findings indicated that despite many pre-existing government reports, and a commitment from all departments involved in the Autism Strategy, inequalities continue to exist.

A survey of professionals in Northern Ireland (n=798), including staff from all Health and Social Care Trusts (HSCTs) and Education and Library Boards (ELBs)<sup>4</sup>, teachers, General Practitioners (GPs), and private sector employees evidenced that autism was very basic (for most max. 1-2 hours, i.e., Level/Tier 1). Analogously, primary qualifications (e.g. Bachelor's degrees or professional qualification) offer no or only very minimal autism training. Yet, while many of the professionals reported that they would welcome the opportunity to improve their autism related knowledge and skills, the comprehensive autism training at the universities in Northern Ireland was not included in the Autism Strategy and Action Plan.

Of course, economic disadvantage is not the only factor that leads to inequality; public awareness and attitudes towards vulnerable people also play a key role in perpetuating or mitigating inequality. The first Autism Module of the Northern Ireland Life and Times survey (NILT; n=1204; BASE project Volume 2) showed that autism awareness is high in the general population, with 82% of respondents being aware of autism and 51% of them knowing someone with autism personally. The survey also showed that the public have a good basic knowledge about the strengths and challenges related to autism and, overall, that their attitudes to children and adults with autism is positive. The NILT Survey autism module also showed that 12% of respondents would be more likely to use a business that employed staff on the autism spectrum.

## Out of the poverty trap and social inequality: Recommendations from BASE

There are numerous measures that should be implemented to make significant differences for individuals and families affected by autism; these are covered in greater detail in the full BASE reports (Volumes 1-5). For this briefing, **4 key recommendations** have been identified.

### 1. Autism awareness and staff training

- Autism awareness in the general population is high and the focus of awareness raising should be directed towards specific sectors:
  - Primary health care providers (e.g., GPs, health visitors, practice nurses);
  - First responders (e.g., ambulance and accident and emergency services);
  - Public sector frontline staff (including benefits agencies and health and social care staff)
  - Employers in both the public and private sector
- Autism skills training for staff in schools and multi-agency autism intervention teams should adhere to international best practice, and it is crucial that local University courses are fully included in the training menu. Short 1-2 hour lectures (Level 1) should not be considered 'training', rather they should be considered awareness raising.

### 2. Early intervention and support for children with autism

- Delays in autism diagnosis should be avoided, either by internally resourcing diagnostic teams or outsourcing autism diagnosis.

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<sup>4</sup> Now the Education Authority (since April 2015).

# Knowledge Exchange Seminar Series 2016-17

- The 'watch-and-wait' approach should be discontinued. It delays onset of interventions during a critical period, when most benefits can be secured.
- Cost-benefit analyses should be conducted for early intensive behaviour- analysis-based interventions compared to other options (such as 'treatment as usual', i.e., the 'eclectic approach'); results of this analysis should guide implementation strategies.
- School attendance, attainment, and pastoral care of children with autism should be monitored and prioritised. Schools should fully utilise available expertise from other agencies, including statutory and voluntary sector.

## 3. Training and employment for young people and adults with autism

- Further /Higher Education attendance, attainment/completion, and pastoral care of young people and adults with autism should be promoted.
- Employment, attainments, and uptake of employment support of adults with autism should be supported;
- Adult autism advisory services (e.g., Northern Adult Autism Advisory Service [NAAAS] and Belfast Adult Autism Advisory Service [BAAAS]) should be expanded province-wide, and should include virtual support systems.

## 4. Families of individuals with autism

- Employment rates in families affected by autism should be monitored and a return to paid employment should be supported.
- Benefit uptake should be monitored and information about financial support disseminated widely.
- Futures planning should be integrated in support packages, with easily accessed information.

## Conclusion

The above recommendations amount to a **spend-to-save policy**. Although many of the measures necessary to meet the recommendations require resourcing, this could be accomplished by a more effective re-distribution of existing resources. The research that underpins these recommendations has clearly identified a number of key areas where present policies have not led to desired outcomes despite considerable investment. It goes without saying that ineffective or inadequate autism support and training carries considerable costs, and leads to poorer long-term outcomes for individuals with autism and their wider families.

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## Knowledge Exchange Seminar Series 2016-17

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## Knowledge Exchange Seminar Series 2016-17

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