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Helping the most vulnerable out of the poverty trap and reducing inequality: Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities: Benchmarking Autism Services Efficacy: BASE Project (Volume 5) Final Report

Dillenburger, K., McKerr, L., & Jordan, J.-A. (2016). *Helping the most vulnerable out of the poverty trap and reducing inequality: Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities: Benchmarking Autism Services Efficacy: BASE Project (Volume 5) Final Report*. Queen's University Belfast.

Document Version:

Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:

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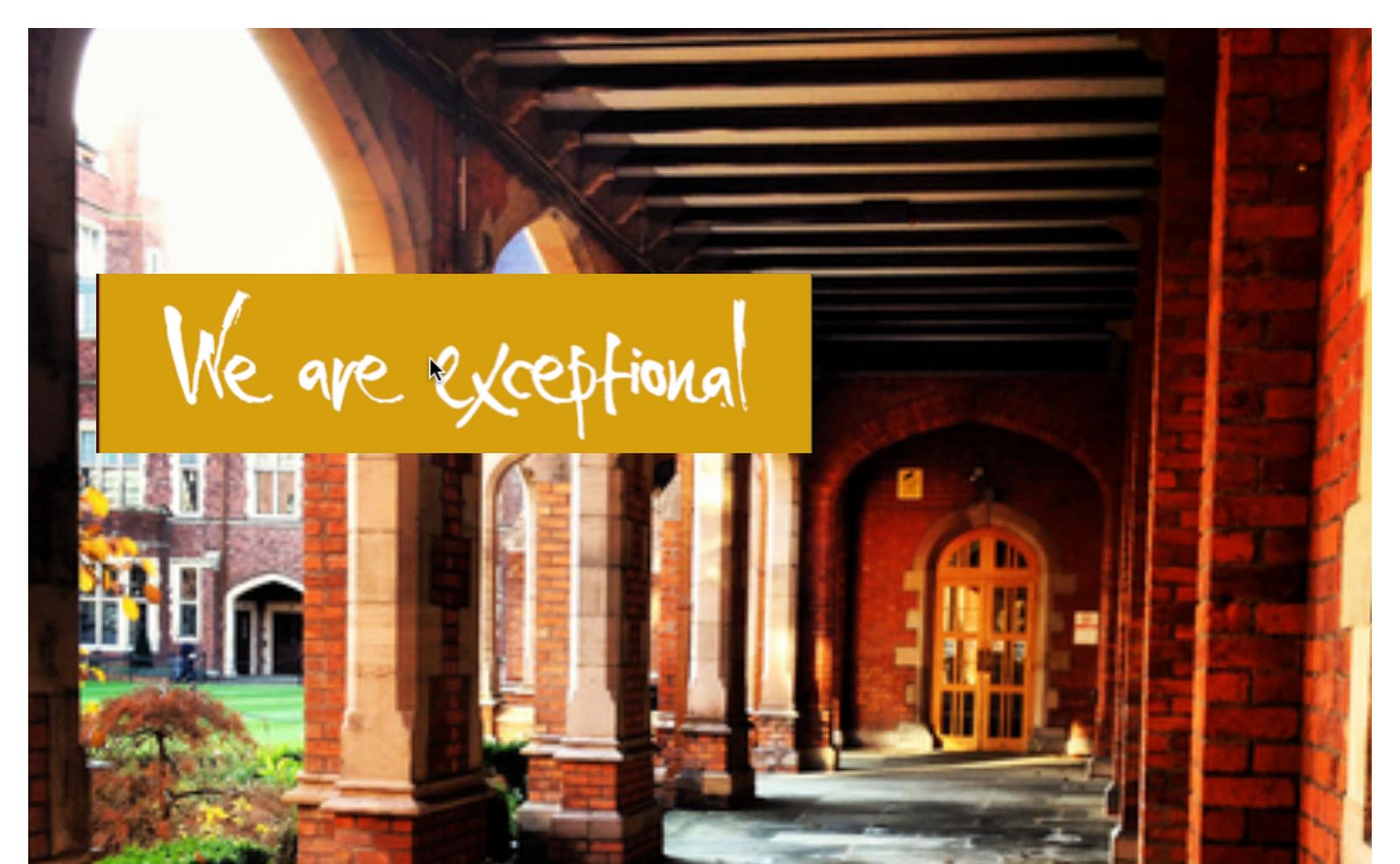
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HELPING THE MOST VULNERABLE OUT OF THE POVERTY TRAP AND REDUCING INEQUALITY:

POLICIES, STRATEGIES, AND SERVICES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER, INCLUDING INTELLECTUAL AND NEURODEVELOPMENTAL DISABILITIES

BASE PROJECT (VOL. 5) FINAL PROJECT REPORT

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MARCH 2015



Queen's University
Belfast

SCHOOL OF
Education
The Centre for
Behaviour Analysis

Funded by



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List of Content	Page
Abbreviations	4
Executive Summary	5
Introduction	9
Baselines: Where are we now?	11
Key findings about autism in NI	27
Benchmarks: Tipping the scales for autism	29
1. Poverty and deprivation	30
2. Cost of autism	31
3. Autism awareness	32
4. Staff training	33
5. Autism diagnosis	34
6. Intervention	35
7. Education	36
8. Post-secondary education and training	38
9. Employment and Housing	39
References	41
Appendix 1: Overview over repeated recommendations	46
Appendix 2: BASE Project Volume 1 Executive Summary	48
Appendix 3: BASE Project Volume 2 Executive Summary	54
Appendix 4: BASE Project Volume 3 Executive Summary	56
Appendix 5: BASE Project Volume 4 Executive Summary	61
Appendix 6: Key policies	72
Appendix 7: Limitations of the research	76

Abbreviations

ASD - Autistic Spectrum Disorder

CDC - Centers for Disease Control and Prevention

COA - Child/ren not on the Autism Spectrum

CWA - Child/ren with Autism Spectrum Disorder

DEL - Department for Employment and Learning

DENI - Department of Education

DETI - Department of Enterprise, Trade and Investment

DHSSPS - Department of Health, Social Services and Public Safety

ELB - Education and Library Board

FE - Further Education

GP - General Practitioner

HE - Higher Education

HSCB - Health and Social Care Board

NICE - National Institute for Health and Care Excellence

OFMDFM - Office of First Minister and Deputy First Minister

RASDN - Regional Autism Spectrum Disorder Network

SEN - Special Educational Needs

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

UNICEF - United Nations International Children's Emergency Fund

Helping the most vulnerable out of the poverty trap and reducing inequality:

Policies, strategies, and services for individuals with Autism Spectrum

Disorder, including intellectual and neurodevelopmental disabilities

(Working title: Benchmarking Autism Services Efficacy: BASE Project)

Executive Summary

The BASE project provides baseline data regarding individuals with autism and it sets benchmarks against which the effect of the Autism Act (Northern Ireland) 2011 and associated Autism Spectrum Disorder (ASD) strategy can be measured. The five integrated Volumes of this project include

Volume 1: *Comprehensive literature review* using a systematic approach on outcomes for individuals with autism and the policies designed to improve those outcomes;

Volume 2: *Northern Ireland Life and Times (NILT) Survey Autism module* to survey public attitudes, knowledge and awareness of autism (n=1200);

Volume 3: *Secondary data analysis* of all relevant NI governmental, departmental and related datasets focussing on education, employment and poverty;

Volume 4: *Qualitative study* using surveys, interviews, and focus groups with individuals affected by autism and key professionals (e.g., educationists, employers, policy makers);

Volume 5: *Final project report* summary including process and outcome record of the BASE Project.

Why are individuals with autism and their families considered amongst 'the most vulnerable' people in Northern Ireland?

Abbreviated summary of key findings:

- 2% of school children have autism; adult autism rates are unknown (Vol. 1); in the UK, up to 3.5% of 11 year-old children are thought to have autism (Vol. 3);
- Autism awareness is high (82%) in the general population, 51% know someone with autism personally (Vol. 2);
- Knowledge about autism is good in the general population (Vol. 2);
- Attitudes towards people with autism are positive (Vol. 2);
- In-service staff training in autism is very basic (1-2 hours) (Vol. 4);
- Local Universities' comprehensive autism training and research was omitted in Autism Strategy/Action Plan (Vol. 1).

Key findings regarding poverty, inequality, and autism:

- The cost of autism per lifetime is estimated at £0.9-1.5 million in the UK (Vol. 1);
- Total cost of autism is £34 billion in the UK (Vol. 1);
- Cost of bringing up a child with autism is up to 6 times greater than for other children (Vol. 1);
- Identification of vulnerability/autism diagnosis is protracted and delayed; watch-and-wait approach in some Trusts means autism diagnosis can take more than 2 years (Vol. 3);
- Early intensive behaviour analysis-based interventions (evidenced as effective interventions) are not available in statutory sector (Vol. 1);
- Children with autism miss school 8-13 days more than other children (Vol. 3), are frequently excluded from (20%), and bullied (20%) in school (Vol. 1; Vol. 3);
- Educational attainment is lower for children with autism (20-40 percentage points lower than other children) (Vol. 3);

- Employment figures for adults with autism are low (approx. 15%; Vol. 1); exact figures not known in NI (Vol. 3);
- Unemployment is high in families with autism (up to 20% higher than other families) (Vol. 3); many parents of children with autism give up employment to care for their child (Vol. 3);
- Income is up to 12% lower in families with autism (Vol. 3);
- Families with autism are likely to live in deprived areas (6 percentage points higher than other families (Vol. 3).

How can people with autism and their families be helped out of the poverty trap and social inequality: Recommendations

Within the four phases of the BASE project, a number of issues were identified that need to be addressed to help families affected by autism out of poverty and inequality.

There are many recommendations that would make significant differences for individuals and families affected by autism and thus have a clear impact on society as a whole (Vol. 1-4). For this abbreviated summary report **4 key issues** have been prioritised that would have the greatest positive impact for individuals with autism and their families across the life course.

1. Autism awareness and staff training

- *Autism awareness* in the general population is high and future autism awareness raising should focus on specific sectors:
 - Primary health care (e.g., GPs, health visitors, practice nurses);
 - First responders (e.g., ambulance services, accident and emergency);
 - Public sector frontline staff (e.g., online awareness training available in NHSCT);
 - 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 (i.e., it is crucial that local University courses are fully included in the training menu).

2. Early intervention and support for children with autism

- *Delays in autism diagnosis* need to be tackled by either internally resourcing diagnostic teams or outsourcing autism diagnosis;
- *Watch-and-wait approach* should be discontinued, as it delays onset of interventions during the critical period (from approx. 18 months-5 years);
- *Cost-saving analysis* should be conducted for early intensive behaviour-analysis-based interventions against other options (i.e., treatment as usual in NI) and results of this analysis should guide implementation strategies;
- *School attendance, attainment, and pastoral care* of children with autism should be monitored (i.e., through School Census). Schools should consistently and fully utilise available expertise from other agencies, including statutory and voluntary sector (i.e., at the moment acceptance of 'outside' expertise is very variable).

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

- *Further Education and Higher Education attendance, attainment/completion, and pastoral care* of young people and adults with autism should be monitored;
- *Employment rates, attainments and uptake of employment support* of adults with autism should be monitored and 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 (Dillenburger & McKerr, 2015).

4. Families of individuals with autism

- *Employment rates* in families affected by autism to be monitored and return to paid employment supported (e.g., facilitate disability child care; good quality

early intensive behaviour analysis-based intervention for pre-school aged children);

- *Benefit uptake* to be monitored and information about financial support disseminated widely;
- *Futures planning* (e.g., independent living) to be integrated in support packages.

The above recommendations amount to a *spend-to-save* policy. Many of the measures necessary to meet these recommendations will require resourcing, however, this does not necessarily amount to new investment, rather it could mean a re-distribution of existing resources.

It appears that some of the current autism spend could be used more effectively with better results. A careful cost-savings analysis should be carried out comparing existing autism spend with the cost of implementing the key recommendations. 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. Ineffective or inadequate autism support and training carries considerable costs, not just in terms of financial budgets, but also in terms of incomplete staff expertise that leads to poorer long-term outcomes for individuals with autism and their wider families.

Helping the most vulnerable out of the poverty trap and reducing inequality:

Policies, strategies, and services for individuals with Autism Spectrum

Disorder, including intellectual and neurodevelopmental disabilities

(Working title: Benchmarking Autism Services Efficacy: BASE Project)

Introduction: *Tipping the scales for autism: From poverty trap to equality*

The Executive's Disability Strategy (OFMDFM, 2012-2015) recognised that nearly 21% of the population in Northern Ireland have some kind of disability and that these people are vulnerable to poverty and inequality. The strategy aimed to raise awareness and focused on access to education, employment, housing, support, services, active citizenship, transport and mobility, transitions, safety and community issues. In order to achieve these strategic priorities the Disability Strategy set out a policy framework to guide the activities of Northern Ireland Departments, improve performance of service delivery, increase the understanding of the needs of persons with a disability, and improve their opportunities.

The Autism Act (Northern Ireland) 2011 placed a duty on the Department of Health and Social Security (DHSSPS) to act as the lead government agency in producing, reviewing and implementing a cross-departmental strategy for Autism as a distinct category of disability. In addition, it placed a duty upon all Government Departments to clearly detail how the needs of individuals with ASD, their families, and their carers are to be assessed and addressed (Northern Ireland Executive, 2014). The cross-departmental Autism Strategy (2013-2020) and the Autism Action Plan (2013-2016) were launched in January 2014,

The BASE (**Benchmarking Autism Services Efficacy**) Project was successful as part of the OFMDFM Research Call (OFMDFM, 2011) aimed to inform policy in relation to *poverty and inequality*. Some 66 projects were funded under this call, covering research related to a large range of people that could be considered vulnerable to poverty and inequality. The BASE Project focused on one such group, i.e., individuals

with Autism Spectrum Disorder (ASD). While some individuals with autism are 'high-functioning' and can achieve good standards of life and inclusion without the need for specific policy attention, the majority experience significant impairment and/or co-occurring intellectual and neurodevelopmental disabilities and require significant levels of support.

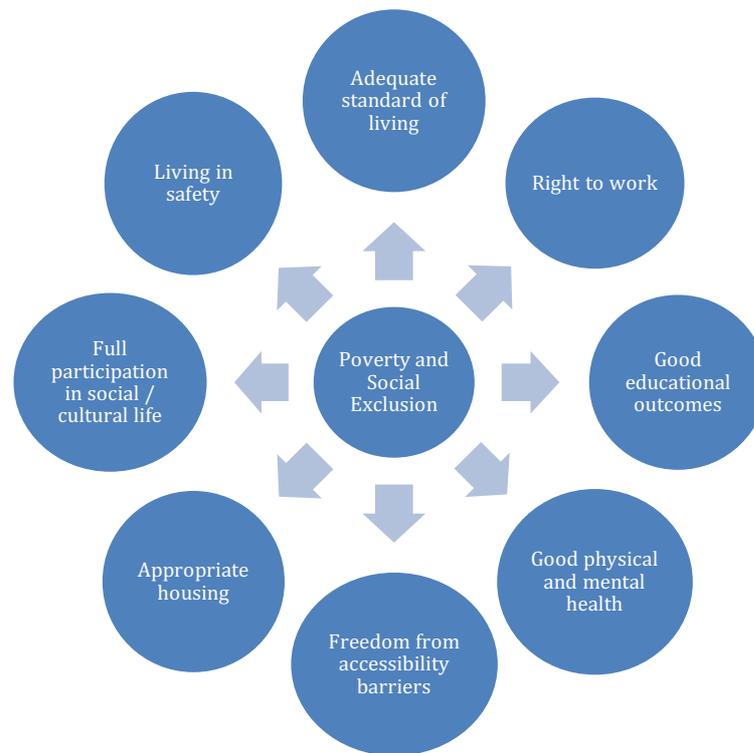
For executive summaries of findings from all four phases of the research see Appendices 2-5. Detailed information on all of the findings is available in BASE Project Reports Vol. 1-4 (download free from www.qub.ac.uk/cba).

The BASE project was a direct result of previous research conducted by the research team with regards to the needs of families affected by ASD in early childhood (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2012; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), examining futures planning of parents caring for their disabled sons/daughters in later life (i.e., 60+ years old) (Dillenburger & McKerr, 2009, 2011), as well as childcare issues across the lifespan (Dillenburger & McKerr, 2014). This body of research clearly pointed towards the need to ensure policies, strategies, and services produce tangible and measurable results when combating social exclusion and poverty of people with disabilities. The BASE project started in 2012 to assess baselines and set benchmarks for services, before the Autism Strategy and the first Action Plan were launched in January 2014 and make findings available to support the review of the first Action Plan (2013-2016) and inform the second Autism Action Plan.

The poverty trap and inequality

The UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) identified a number of equality, social inclusion, and poverty related indicators (Figure 1) that were adopted into the framework of Lifetime Opportunities (the Anti-Poverty and Social Inclusion Strategy for Northern Ireland; OFMDFM, 2006). The UNCRPD underpinned the rights-based rationale of the BASE Project research.

Figure 1: UNCRPD: Rights for individuals with disabilities, including autism.

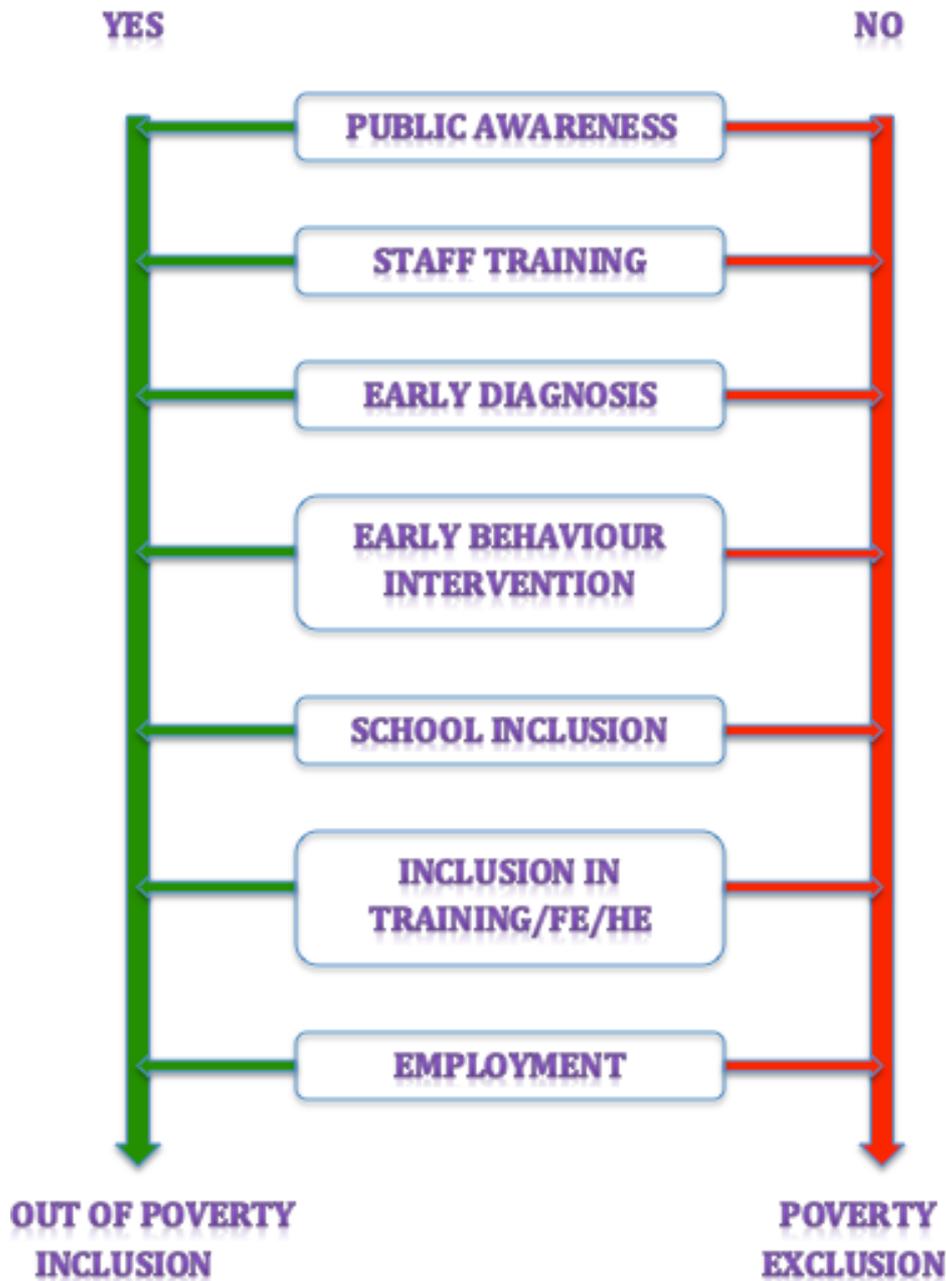


Establishing baselines: Where are we now?

An extensive review of the literature (BASE Project Vol. 1) identified the factors that contribute to poverty and inequality for individuals with autism and their families and recognised mechanisms that have the potential to help them out of the poverty trap and thereby reduce inequality, including:

- increased public awareness;
- appropriate and high quality staff training across the public and private sector;
- timely diagnosis;
- availability of early intensive behaviour analysis-based interventions;
- quality of education and training; and
- availability of employment for adults with autism and their parent/caregivers (Figure 2).

Figure 2: Mechanisms involved in tipping the scales for autism: Out of the poverty trap and towards equality.



BASE Project Vol. 2 reported on a general population survey (n=1204) that assessed public attitudes, knowledge, and autism awareness, by including an autism module in the Northern Ireland Life and Times (NILT 2012) Survey, for the first time.

BASE Project Vol. 3 described the comprehensive secondary data analysis of all relevant NI autism related datasets, that focussed on education, employment, and deprivation and poverty.

BASE Project Vol. 4 added a qualitative perspective to the project by exploring the experiences of a number of individuals with autism and their parents or carers (n=37) and the staff (both public and private sector) who are tasked with supporting service users affected by autism (total number of participants, n=848), thus building on previous research on NI autism service user experiences (Dillenburger et al., 2010; Dillenburger et al., 2012; Dillenburger, Keenan, Gallagher, & McElhinney, 2004; Dillenburger, Keenan, & Gallagher, 2015; Dillenburger & McKerr, 2009, 2011, 2014; Keenan, Dillenburger, Doherty, et al., 2010).

BASE Project Vol. 5, the present volume, reports on the triangulation of findings from the four phases of the BASE Project and draws out benchmarks and recommendations.

Identification of vulnerability: Autism diagnosis and prevalence in Northern Ireland

In Northern Ireland, 2% of the school population are recorded as having autism (DHSSPS, 2014), although this figure is likely a significant underestimation. In fact, the secondary data analysis (BASE Project Vol. 3; Dillenburger, Jordan, McKerr, & Keenan, 2015) revealed that increasing number of parents who took part in the Millennium Cohort Study (born in 2000; UK data: including NI; n=18,522) were told that their child has autism:

- 0.9% (1:109) when the children were 5-year olds (in 2005);
- 1.8% (1:55) when they were 7-years olds (in 2007);
- 3.5% (1:29) when they were 11-years olds (in 2011).

In 2014, the *Young Life and Times* (YLT) Survey and the *Kids Life and Times* (KLT) Survey included an autism module for the first time (Dillenburger, McKerr, & Jordan,

2015b). In the YLT Survey (total n=1034), 3.1% of Northern Irish young people (aged 16 years of age) identified themselves as being on the autism spectrum; and in the KLT Survey (n=2319), 2.7% of the children (aged 10-11 years) identified themselves as being on the autism spectrum. Local prevalence estimates for adults with autism are not available in Northern Ireland.

Identification of poverty and inequality

While poverty and inequality are separate concepts that are not necessarily co-occurring, they are inexorably linked and helping people to move out of poverty impacts on their social as well as economic equality. In Northern Ireland, 37% of primary school children with autism are entitled to free school meals (7 percentage points more than children without autism), an indicator often used to identify deprivation (BASE Project Vol. 3).

Latest figures from the 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 (22% compared to 15%). These figures constituted an upward trend over the past five years and the differential is growing. While these figures do not specify the disability, they include the growing number of families affected by autism, which means that it is likely that at least 22% families affected by autism experience poverty and low income (BASE Project Vol. 3).

The 'cost of autism' in the UK is estimated to be about £0.9-1.5 million across a single lifetime (depending on level of functioning) with the total annual cost estimated to be £34 billion per year (Buescher, Cidav, Knapp, & Mandell, 2014). Most of the cost is due to lifetime care costs and unemployment of individuals with ASD and their parents. 'Costs were much higher in early childhood than for older children in the United States; in contrast, annual costs for children in the United Kingdom increased with age' (Buescher et al., 2014, p.724; cf., BASE Project Vol.1).

Almost half of parents of children with ASD adjusted their lifestyle either by leaving employment (20%), reducing their working hours or limiting their occupation choices because of caring responsibilities for sons and daughters with autism (BASE Project Vol. 3; Vol.4). Consequently, these families are twice as likely as other families to have no employment-based income at all. Recent studies have indicated that parents find difficulty in obtaining good quality daycare for their children with autism (Dillenburger & McKerr 2014; Employers for Childcare, 2011); there is an additional cost for child-minders who take on children with disabilities because they may reduce the number of places they can offer to provide adequate supervision and stimulation, and where children have more challenging behaviours this is particularly difficult, with some parents being asked to remove their child from formal childcare as staff cannot cope (Employers for Childcare 2011).

Even parents who were in employment were on average £28-£60 worse off per week than other families (BASE Project Vol. 3), while experiencing child rearing expenses that were more than 6-fold of child rearing expenses for children without disability (Contact a Family, 2012; cf., BASE Project Vol. 1). Parental productivity loss accounts for 36% of the annual cost of autism (Buescher et al., 2014; cf., BASE Project Vol. 1). Of course, economic poverty 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 (see Figure 2).

Public awareness

The term 'autism' has become the 5th most used search term on Google (Ward, 2014). The 2012 NILT Survey found that autism awareness was high in the general population in Northern Ireland (82%; BASE Project Vol. 2; Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013). Most respondents had a fairly accurate understanding of the strengths and challenges faced by people with autism and public attitudes towards the inclusion of individuals with ASD were generally positive (Dillenburger, McKerr, Jordan, Devine, & Keenan, 2014). Half of the general population (51%) knew someone with autism in their own family or close friendship

circle. Autism awareness was lowest for those who had not completed higher education, for ethnic minorities, for males, and for those with no Internet access (BASE Project Vol. 2).

Furthermore, the 2012 NILT Survey found that over half of the general public (58%) realised that autism is not necessarily a 'lifelong' disability (cf., Fein et al., 2013) and there was strong support for evidence-based behavioural interventions (77%), especially in the early years. There was also support for family-based caring rather than residential care (64%). The public was confused about interventions that were not evidence-based and they were uncertain about which Department was responsible for ASD care and support (BASE Project Vol. 2).

Interestingly, these findings were reflected in the 2014 Young Life and Times (YLT) Survey of young people (16-year olds) and the Kids Life and Times (KLT) Survey of children (11-year olds) in Northern Ireland (Dillenburger, McKerr, & Jordan, 2015b). The YLT Survey found that 80% of the young people were aware of autism and 72% knew someone with autism personally, while of the younger children, 50% were aware of autism and 43% knew someone with autism. Knowledge about autism was reasonably accurate and attitudes were positive and supportive in both groups.

In sum, there is evidence that the general population is relatively well aware, knowledgeable, and positively disposed towards social inclusion and equality of persons with autism.

Support mechanisms: Staff training

A well-trained workforce is necessary in all departments (particularly in DHSSPS and DE) to ensure that inequalities are reduced and that vulnerable individuals and their families are supported out of poverty and towards equality.

Since the Report of the Task Group on Autism (DENI, 2002) a considerable amount of public resources have been spent on an extensive range of governmental policies,

reports and guidelines relevant to services for individuals with ASD and their families in Northern Ireland (n=70+ reports and guidelines etc) that pre-date the Autism Strategy (2013-2020) (BASE Project Vol. 1; Dillenburger, McKerr, & Jordan, 2014b). Many of these reports repeated the same recommendations (for *traffic light* indication of how far these recommendations have been addressed see Appendix 1).

One of the key recommendations in most of these reports was the necessity to provide improved staff training and expertise. Clearly, given the specialist nature of autism, without a well-trained staff Departments cannot fulfil their role in relation to reducing poverty and inequality for people with autism.

Yet, despite the fact that most of the multidisciplinary professionals who participated in the BASE project (BASE Project Vol. 4; Dillenburger, McKerr, & Jordan, 2014a) had some contact with individuals on the autism spectrum (teachers more frequently than other Education and Library Board (ELB) staff or Health and Social Care (HSC) Trust staff), initial professional qualifying training does not routinely include much by way of training in ASD and where it exists, it is usually limited to one or two lectures or less across the entire degree (Dillenburger, Röttgers, et al., 2014; Keenan et al., 2014; cf., BASE Project Vol.1). Consequently, much rides on in-service and post-qualifying staff training. There are a number of training providers, both within the statutory sector by HSC Trusts, such as the Northern Trust online autism training; Departments, such as the DE's Middletown Centre for Autism; DEL's Higher Education Institutions; and the voluntary sector.

In Northern Ireland, ASD training is categorised according to the 3 levels or tiers identified by the National Autistic Society:

- **Level/Tier 1** equates to brief autism awareness sessions, usually a 1-2 hours lecture/talk,
- **Level/Tier 2** is usually a one day seminar, aimed at staff who directly support a child with autism;
- **Level/Tier 3** commonly takes 1-2 days and aims at building on existing knowledge for those who are taking a lead in autism provision.

Given the brevity of these events, the term 'training' needs to be used cautiously. At best, even at Level 3, these sessions offer basic introductions to autism awareness or they focus briefly on specific issues, such as mental health or sensory issues (e.g., DE, 2015). Obviously, listening to a talk about autism for a few hours is not to be equated with professionally approved training in knowledge, values, and practical, evidence-based skills that are designed to address the challenges associated with autism.

The BASE Project Vol. 4 revealed that, of the school teachers who participated (n=43) about $\frac{3}{4}$ said that they had received training; 47% had attended Level 1 autism awareness training and 13% had attended Level 2 training. None of the participating teachers revealed that they had received Level 3 training or above. Of the ELB staff who participated (n=40), 37% had attended training in autism (mostly Level 1).

Similarly, of the HSCT staff (total n=569) who responded to the BASE Project survey very few had received Level 1 (19%) or Level 2 autism training (10%).

For those who require more comprehensive training or expertise, all three Universities in Northern Ireland offer extensive autism training for professionals at various levels:

- Pre-graduate level (UU School of Psychology¹);
- Undergraduate level (Open University²; QUB School of Education³);
- Post-graduate level (UU School of Psychology⁴; QUB School of Education⁵).

This extensive menu of third level autism training was omitted in the Autism Strategy (2013-2020) or Action Plan (2013-16) and thus constitutes a relatively untapped resource available to combatting poverty and inequality through improved staff training and expertise (cf., BASE Project Vol. 1). While there may be a perception that University-based training is costly, an actual cost-savings analysis

¹Certificate of Professional Development (blended learning)..

²Understanding Autism (online module).

³Open Learning Courses: Understanding Autism (10 hour campus-based); Registered Behavioural Technician (40 hours online).

⁴ MSc Applied Behaviour Analysis (since 2005; professionally approved www.bacb.com), with placement opportunities in the New England Centre for Children, Boston, USA.

⁵ MSc Autism Spectrum Disorder (campus-based since 2002); and MSc Applied Behaviour Analysis (online/blended since 2014; professionally approved www.bacb.com). All modules are available as stand-alone short courses.

has not yet been conducted to compare University-based training and other publicly funded training providers. A cursory look at the figures suggests that such an analysis is likely to demonstrate significant potential savings in favour of HE sector training.

Early diagnosis

In order to help vulnerable people out of poverty and inequality and/or put in place preventative strategies, it is necessary to identify vulnerability as early as possible. With regards to autism, this translates into the need to diagnose as early as possible.

The secondary data analysis of the Millennium Cohort Study (BASE Project Vol. 3) revealed that children later diagnosed with ASD showed very early behavioural and medical indicators that should raise concern. As young babies, these children were more likely than other children to have physical health problems, including problems walking on level ground, delays in speech and language, problems with hearing and eyesight, and asthma; when they were 3 years of age, they experienced poorer emotional and social health and this difference increased significantly by the time they were 7 years of age. These findings confirm international findings evidencing that diagnosis is possible much earlier than presently practiced in Northern Ireland, thus allowing for early intensive behavioural interventions or parent training to start much earlier (Dawson et al., 2012).

A study of 100 children with autism in NI found that for many the diagnostic process took over 2 years, by which the time children are aged 4-5 years of age (Keenan, Dillenburger, Doherty, et al., 2010). A number of parents who took part in the BASE Project (Vol. 4) confirmed these findings and reported that an autism diagnosis was necessary for access to intervention and financial benefits; yet, for over half of the referrals in Northern Ireland, ASD diagnosis was 'deferred' for 12 months and more (FOI, 2013).

There are at least 1300 children waiting for diagnosis in Northern Ireland (Megaw 2015) and despite efforts to reduce this waiting list (Regional Autism Spectrum Network; RASDN, 2011), the numbers are rising. As of July 2015, approximately 200 children are referred per month and only approximately 50% of these referrals (approx. n=100) are being processed, most of them outside the recommended time line (Megaw, 2015). Deferring diagnoses or keeping 'watch-and-wait' lists is highly controversial (Ozonoff et al., 2015), especially because of the detrimental effect on parental stress, postponement of services and benefits for families, and loss of the potentially positive effect of early intensive behavioural intervention (Dawson et al., 2012; Rogers, 2014). Thus, late diagnosis has a significant negative impact on poverty and inequality for these families.

The same is true for delays in receiving Special Educational Needs Statements. Although the Special Educational Needs Code of Practice states that assessments and statements should be made as quickly as possible, '59% of statements (1,317) were issued outside the statutory 26 week limit, although the Department notes that nearly all cases were subject to valid exceptions... There were variations by ELB, with 71% of statements (347) issued by the BELB subject to delays compared to 51% at the NEELB (194)' (Perry, 2015, p4-5).

Adult diagnostic services are significantly under-staffed in Northern Ireland, e.g., one of the Trusts had no (n=0) staff time allocated for adult autism diagnosis (DHSSPS, 2015), despite the fact that adult diagnoses have rather narrow criteria for referral, e.g., the adult has to have clinically significant challenges and difficulty in daily functioning (HSCB, 2012). As for adult interviewees with autism (n=5) in the BASE Project, most sought an autism diagnosis after another family member was diagnosed, usually their own child and they did not expect to receive post-diagnostic services, instead they expected the diagnosis to help them understand their past life experiences and problems. Two of the female adult participants had funded diagnosis privately; four of the participating parents also had sought privately funded diagnosis for their daughters. All of the participating adults with autism had experienced mental health difficulties, such as depression and anxiety (BASE Project Vol. 4).

In other parts of the UK, there are examples of good practice and collaborative working with regards to adult diagnosis that could be adopted in NI to improve diagnostic services for adults (Case Study 1).

Case study 1: Autism Diagnosis Research Centre in Southampton

The Autism Diagnostic Research Centre (ADRC) in Southampton is a unique UK-based service for adults suspected of having autism spectrum disorders. The service brings together a range of clinical specialists with the aim of:

- Determining a formal diagnosis based on objective data;
- Addressing the possibility of additional clinical conditions which frequently occur;
- Identifying an individual's cognitive strengths, as well as possible difficulties;
- Providing a report that helps the individual better understand their own condition and others understand the conditions necessary for habilitation, in order to enable those with a diagnosis to live more engaged, productive, and fulfilling lives; and
- Provide a number of focused post-diagnostic services.

The ADRC started as collaboration between the University of Southampton and private business (run by a father of an adult with autism) to respond to the need for adult diagnosis, that was not met within the health services. ADRC developed into a stand-alone sustainable centre.

The clinical team, mainly employed on a pro-rata basis, comprises clinical psychologists, neuropsychologists, a specialist educational psychologist, a forensic psychologist, assistant psychologists, consultant psychiatrists, specialist nurse therapists, and an occupational therapist. Together they have a wealth of experience and expertise in the field of ASD, and come from a variety of different backgrounds, including child and adult health services, learning disability services, and adult mental health services.

Once a referral has been received from the GP together with confirmation of funding, the person will be contacted by post. They will be asked to complete a form giving permission for ADRC to contact their GP to obtain details of their previous medical history.

The information from the GP and the scored self-rating measures are collated and discussed at one of ADRC's monthly inter-disciplinary team meetings.

The person is then invited to attend for an assessment appointment. Following this process a report is compiled that belongs to the person who has been assessed. This report gives the diagnosis (if that is appropriate), considers dual or differential diagnosis (through the psychiatric assessment), identifies strengths and weaknesses (through the neuropsychological assessment), and makes recommendations for strategies and other possible avenues of support.

Recently, ADRC has complemented its assessment and diagnostic service with both adapted Cognitive Behaviour Therapy and Relationship Counselling. (Case study extracted from www.adrc.co.uk).

Early intervention

There is extensive and unequivocal evidence (National Autism Center (NAC), 2015) that early intensive behavioural interventions (i.e., based on the scientific discipline of Applied Behaviour Analysis; ABA⁶) can enhance the quality of life of individuals with ASD and their families (BASE Project Vol. 1) and lead to optimal outcomes (Fein et al., 2013; Orinstein et al., 2014).

Without early intensive behaviour analysis-based interventions the outlook is bleak. Howlin, Savage, Moss, Tempier, and Rutter (2014) conducted a 40-year follow-up of adults (n=65; mean age 44 years), whom they had diagnosed as children in the 1970s. They found that 75% of these adults had unchanged IQ level (≥ 70) since their childhood assessment and only minor improvements in terms of language, while 25% of them could not be assessed due to severe aggressive or self-injurious behaviours and had not developed language above a 3-year level. Howlin et al. (2014) concluded that '[a]lthough many attended specialist autism schools as children, none had access to the intensive, early behavioural programmes that are available today' (p.56). Controversially however, Howlin et al. (2014) go on to assert that only 'some' people in the UK believe that intensive, early behavioural programmes are effective, despite the overwhelming international evidence in their favour (e.g., Surgeon General, 1999; NAC, 2015) and Howlin et al.'s own findings that lack thereof has detrimental long-term consequences (Howlin, Goode, Hutton, & Rutter, 2004, Howlin et al. 2014).

⁶ NB: Misinformation about ABA is very widespread in Northern Ireland, due to lack of training in the science of Behaviour Analysis of practitioners and those who have been involved in the writing of existing autism reports (see BASE Project Vol. 1; Dillenburger et al., 2014). This has led to an erroneous view of ABA as 'one intervention for autism', 'not holistic', 'only suitable for children with autism', 'not individualised', or even 'a commercial product' (Dillenburger et al., 2014; Dillenburger, 2011). These inaccurate caricatures have led to wide-spread censure of ABA in NI.

An accurate account, defacto, is that ABA is the application of the scientific discipline of Behaviour Analysis to socially important areas (Cooper, Heron, & Heward, 2007). Behaviour analysis, like other sciences such as Medicine or Biology, provides the body of knowledge on which applications are based. The focus of Applied Behaviour Analysis (i.e., ABA) is the enhancement of behavioural repertoires (of service users, caregivers, staff etc.). ABA is used in many areas, such as education, business, health, as well as autism. The focus is on enhancing quality of life by expanding behavioural repertoires and therefore increasing behavioural choices people can make. The Behavior Analyst Certification Board (www.bacb.com) is the professional body responsible for certification of professionals and approval of training in ABA (BACB, 2015). In NI, both UU and QUB offer BACB approved Masters courses in ABA and shorter ABA courses at pre-or undergraduate levels (BASE Project Vol. 1).

Evidently, early intensive behaviour analysis-based interventions lead to positive long-term outcomes (BASE Project Vol. 1) and thus constitute a crucial mechanism to help vulnerable people with autism out of poverty and inequality. Based on a cost-savings analysis, Case Study 2 is an example of good practice in relation to early behaviour analysis-based intervention that could function as a model for implementation in Northern Ireland.

Case study 2: Ontario Autism Intervention Program

The Autism Intervention Program (AIP) in Ontario has been in place providing intensive behavioural interventions (IBI) to children with autism spectrum disorder since 1999. IBI are evidence-based interventions based on applied behaviour analysis (ABA) used in the family home or in an IBI centre.

A number of lawsuits initiated by parents sparked political interest in accommodating the needs of children with autism. In 2000, the Ministry of Children and Youth Services established province-wide “Intensive Behavioural Intervention” (IBI) as a service for these children up until age six. Research demonstrated the effectiveness (including cost effectiveness) of this program (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006; Perry & Condillac, 2003; Perry et al., 2011; Turan, 2014) and because of parent demand, age cutoffs have been removed and school-based ABA services are now available (PPM-140, 2007).

In 2004, the Autism Society of Canada released a White Paper stating that ‘[w]ith what we do know from evidence based research, the lifetime costs of assisting a person with autism can be cut by 50% if he/she receives an early diagnosis, effective treatments, and adequate family supports; clearly, this is in the financial interests of governments and taxpayers’ (Autism Society Canada, 2004, p4).

In terms of how the programme is actually delivered, each of a number of core features varies on a local basis. For example, the interventions are delivered at home, in a classroom, or in a centre, using published curriculum guide or curricula that are cooperatively developed between clinical supervisors and parents. The features that are relatively static across the province are a) the delivery of an “intensive” program (25-40 hours per week) over a sustained period of time (i.e., at least two years); b) having a “behavioural” focus, meaning that changes in the behaviour of children are sought in measureable, observable ways; c) “early,” meaning that children are receiving the intervention at a young age (i.e., less than 4 years of age); d) be “ABA,” in that the strategies are based on the principles of applied behaviour analysis.

The services are delivered from nine regional agencies across the province in partnership with community agencies. Once a child has been given a diagnosis of autism, they are then eligible to apply for the IBI program with their regional centre. The programmes are delivered under the direction of a clinical director i.e., Board Certified Behaviour Analyst (www.bacb.com) who oversees a team of clinical supervisors and therapists.

IBI is available to all eligible children with autism and it is argued that these services will continue to have long-term cost-benefits (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006). (Case study extracted from Turan, 2014)

Despite the fact that Applied Behaviour Analysis (ABA)-based interventions were recommended in the Task Group Report on Autism (DENI, 2002) and there is a high demand in Northern Ireland (Dillenburger et al., 2012; 2015), these interventions are still not available through the HSC Trusts or the Department of Education and

‘when parents seek support for such a service the Boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect’ (DENI, 2002). While parents are often well-informed (Dillenburger et al., 2010), generally statutory sector staff are not trained to professionally approved levels in Behaviour Analysis (www.bacb.com). Qualifying training for allied health professionals or teachers does not include training in ABA (Dillenburger, Röttgers et al., 2015). In fact, of the Board Certified Behaviour Analysts (BCBA) who work in Northern Ireland, five work in Higher Education (QUB and UU), four work in the voluntary sector (PEAT⁷), and most of the others work in the private sector⁸ (BACB, 2015).

The 2013 National Institute for Health and Care Excellence guidelines on the management of children with autism (Guideline 170) did not make specific reference to ABA, however, most of the recommendations were based on behaviour analysis-based procedures (e.g., antecedent interventions, video modelling, picture schedules), especially with regards to psychosocial interventions to address behaviours that challenge, and they advise that these interventions should be delivered by trained professionals, i.e., ‘psychosocial intervention (informed by a functional assessment of behaviour) [are recommended] as a first-line treatment’ (NICE, 2013, p11).

More recent NICE guidelines for Challenging Behaviour (Guideline 11, 2015) explicitly include behaviour analysts in the list of relevant professionals (2.1.4; 6.4.3; and 14.1.5). Therefore, given that challenging behaviours are common in children and adults with autism, ABA-based interventions and appropriately qualified staff (www.bacb.com) should be available within the statutory sector; in the USA, legislation such as the Affordable Care Act covers ABA-based interventions for autism

⁷ The charity *Parents’ Education as Autism Therapists* (PEAT; peatni.org) is a parent-led charity, founded in 1997, that offers ABA-based training to parents and professionals and supervises home-based intervention programmes. PEAT is resourced through fundraising, e.g., Big Lottery, Children in Need, and, when grants are not available, modest parent contributions. PEAT does not receive any core Government funding.

⁸ Reliance on the private sector for ABA-based provision has left the impression that ‘ABA is expensive’ (Freeman, 2003; Keenan, Dillenburger, Moderato, & Röttgers, 2010). However, it is not the application of the science that is expensive, rather the expense is incurred when open market forces, i.e., private sector, operate in a vacuum of statutory service provision.

under 'essential health benefits' and the Board Certified Behaviour Analyst (BCBA) is a licensed professional in an increasing number of States (AutismSpeaks, 2015, p1).

In contrast, in NI, interventions for autism are based on a nonspecific 'eclectic approach' (DENI, 2002) and remain variable and limited, e.g., following diagnosis, parents are offered a once-off visit and/or a one-day awareness raising workshop (McConkey, Kelly, & Cassidy, 2007).

In addition, some parent participants in the BASE Project (Vol. 4) experienced difficulties in communicating with professionals and were frustrated with professional 'hostility' when they were looking for behaviour analysis-based interventions. These findings confirm previous research that lack of adequate staff response can heighten the emotional stress and impact of an autism diagnosis (Burrows, 2012; Dillenburger et al., 2010; Dillenburger, 2011; McConkey et al., 2007). Only a minority of parents had access to disability social workers who were generally viewed as the gateway to other services (e.g., respite/short breaks). Social work input was usually dependent on the individual having co-existing learning disabilities, with an IQ threshold of <70.

The delay in onset of interventions, caused by delayed diagnosis, means that most children with autism in NI miss invaluable opportunities during pre-school years (i.e., exploiting childhood brain plasticity through early ABA-based interventions; cf., Dawson, 2008) and consequently, potential long-term savings to the tax payer (up to £1million across a single lifetime) are missed (Buescher et al., 2014; Motiwala et al., 2006).

School achievement and inclusion

In Northern Ireland, 2% of school children were reported to be on the autism spectrum; this figure has been rising by 0.2% annually (DHSSPS, 2014). Based on UK figures, it is likely that about two thirds of the children with autism in mainstream

schools have a Special Educational Needs (SEN) Statement (BASE Project Vol. 3; Dillenburger, McKerr, & Jordan, 2015).

Parents worry that their children with autism received a poorer education than other children, have fewer educational choices or received inadequate support in school because of their disability (Keenan, Dillenburger, Doherty, et al., 2010). Children with Asperger syndrome miss school between 2-3 weeks more than other children and many miss a whole school term or more (BASE Project Vol. 3); 20% of these children experience formal and informal exclusions and bullying (Ambitious about Autism, 2014). Not surprisingly therefore, children with autism lag behind at school and 49-67% leave school without 5 GCSEs (A*-C or equivalent) compared to approx 33% of other children (BASE Project Vol. 3).

Inclusion in post-secondary education and training

Students with autism are proportionately well represented in Further Education (FE; 0.7% of the student body) and Higher Education (HE; 0.45% of the student body) (BASE Project Vol. 3; cf., Dillenburger, Jordan, et al., 2014) and although this does not fully reflect the estimated prevalence of autism among the peer group, DEL initiatives, such as the Widening Access Strategy and increased support budget for reasonable adjustments for students with disabilities in FE appear to be effective. Retention monitoring data are relatively recent (HE/FE students with autism are monitored since 2010/11) but early indications are that these students complete their courses (BASE Project Vol.3).

However, while students with autism chose to study a wide range of different subjects, from information technology to health to social care and engineering, the overall the level of study was lower than that of other FE/HE students, i.e., often focussing on essential and vocational skills at Level 1 entry (37% vs 23%) (BASE Project Vol. 3).

In the short-term, only 5-6% of school leavers in NI appear to be 'Not in Education, Employment, or Training' (NEET) (BASE Project Vol. 3). While 3% of school leavers

with autism gain employment (BASE Project Vol. 3), no long-term data exist on training outcomes and best available NEET estimates are based on self-selected online survey responses from adults with autism in the UK (total response n=2,938; Bancroft, Batten, Lambert, & Madders, 2012), indicating that one third of these young people are NEET, representing more than twice the rate of other young people.

Employment

While exact employment figures are not available, the BASE Project (Vol. 3) found that only small number of adults with ASD (n=99) had benefitted from DES employment provision since 2002. For more general employment figures in the UK, best estimates rely on a survey sample that found 15% employment amongst adults with autism (Rosenblatt, 2008).

Unemployment is linked to risk of mental health problems, lack of societal integration, criminal justice engagement, and poverty (Billstedt, Gillberg, & Gillberg, 2011). For adults with autism there are a number of barriers to employment, including employer concerns about potentially aberrant behaviours (Dillenburger, McKerr, & Jordan, 2014) and employees with autism being bullied by colleagues (Stewart, 2008). Notwithstanding these difficulties and in line with previous research (Rosenblatt, 2008), adults with autism (n=5) who participated in the BASE project expressed a high willingness to work and welcomed work-related placements and employment related skills training. The new Employment and Skills Strategy for Northern Ireland (European Social Fund initiative) aims to reduce economic inactivity, and improve employment opportunities for disadvantaged groups (including those with autism). The effectiveness of this initiative remains to be assessed.

The Northern Ireland Life and Times (NILT) Survey autism module (n=989; BASE Project Vol. 2) showed that by having an explicit policy to employ individuals with autism, business would not lose out, in fact, such a policy could even enhance business; i.e., the vast majority of respondents (86%) said that they would continue

to use a supermarket (i.e, a business) with this policy, and 12% said that they would be more likely to use such a business.

However, in line with previous research (Rosenblatt, 2008), even employers who realise the potential advantage of offering employment to individuals with autism emphasised that this demanded considerable additional resources. Therefore, while employers are prepared to 'go the extra mile' to employ individuals with autism in the short-term, this may not be feasible in the long-term without additional resources.

Accommodation and leisure

About two thirds of all adults with autism live at home with their ageing parents, while others live in residential care or supported housing. While only very few adults with autism live completely independently, most would like more independence, although they realise that they would require suitable housing options and support with basic life skills (BASE Project Vol. 1; Dillenburger & McKerr, 2014). Most ageing parents (>70%) have not made plans for the future for their sons or daughters with autism (Dillenburger & McKerr, 2009).

Many adults with autism have problems making and keeping friends. Services that help inclusion, such as befriending and social skills training, are important and likely to provide health as well as social benefits, protect against stress, and improve quality of life. Without sufficient support, adults with autism and their caregivers experience isolation from leisure and community activities and family functioning is affected adversely, at times to breaking point, leading to marital problems, and divorce. Respite care or short breaks are considered supportive, yet eligibility criteria exclude many individuals, e.g., application of an IQ threshold for social work support or referral for services (Dillenburger, McKerr, et al., 2015).

Baseline conclusions

Key findings about autism prevalence and public awareness:

- At present, best estimates are that 2% of school children in NI have autism; adult autism rates are unknown (BASE Project Vol. 1);
- In the UK, up to 3.5% of 11 year-old children are thought to have autism (BASE Project Vol. 3);
- Autism awareness is high (82%) and knowledge about autism is relatively good in the general population (BASE Project Vol. 2);
- Attitudes towards people with autism are positive (BASE Project Vol. 2);
- In-service staff training in autism is generally very basic (1-2 hours) (BASE Project Vol. 4). Local University autism training was overlooked in the Autism Strategy and Action Plan (BASE Project Vol. 1).

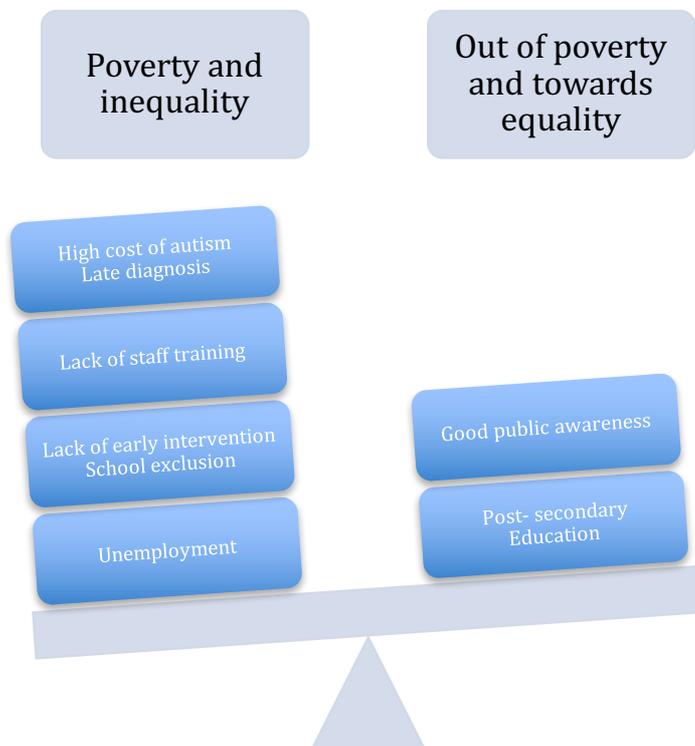
Key findings regarding poverty, inequality, and autism:

- The cost of autism per lifetime is estimated £0.9-1.5 million in the UK, with a total cost of autism at £34 billion in the UK;
- Although there is no established direct link between poverty and autism, there are numerous indirect links due to social, economic, and emotional stresses, isolation, exclusion, and unemployment; e.g., the cost of bringing up a child with autism is approx. 6x greater than for other children (BASE Project Vol. 1); income is up to 12% lower in families with autism than for other families (BASE Project Vol. 3);
- The identification of vulnerability (i.e., autism diagnosis) is protracted. Watch-and-wait approach in some Trusts means autism diagnosis can be delayed for more than 2 years (BASE Project Vol. 3);
- 'Early intervention' in Northern Ireland is mostly brief and variable (e.g., a once off 1-3 hour visit), while internationally recognised best practice (i.e., early intensive behaviour analysis-based intervention) is not available in the statutory sector (BASE Project Vol. 1);

- Children with autism miss school 8-13 days more than other children (BASE Project Vol. 3) and are frequently excluded (20%) and bullied (20%) in school (Vol. 1; Vol. 3);
- Educational attainment is lower for children with autism (20-40 percentage points lower than other children) (BASE Project Vol. 3);
- Employment figures for adults with autism are low (approx. 15%; BASE Project Vol. 1), however, exact figures are not known in NI (BASE Project Vol. 3);
- Unemployment is high in families with autism (up to 20% higher than other families) (BASE Project Vol. 3) and many parents of children with autism give up employment to care for their child (BASE Project Vol. 3);
- Families with autism are likely to live in deprived areas (6 percentage points higher than other families; BASE Project Vol. 3).

On balance, BASE Project findings showed that, while there are some signs of progress in relation to public awareness and post-secondary school progression, the scales were still tipped firmly against individuals with ASD towards poverty rather than equality and inclusion (Figure 3).

Figure 3: The Scales of Poverty and Inequality (SPI) Model: Baseline in Northern Ireland⁹



⁹ The term 'Early Intervention' used in this figure is to be understood as early intensive behaviour analysis-based intervention (cf., main text)

Benchmarks: Tipping the scales for autism

'If we keep doing what we're doing, we keep getting what we're getting' (Stephen R. Covey).

Benchmarks and recommendations were developed on the basis of BASE Project findings. The aim of these benchmarks and recommendations is to help policy makers, practitioners, and those directly affected by ASD to make decisions that help individuals and families affected by autism out of the poverty trap and reduce inequality.

Benchmarks and recommendations in Tables 1-9 are linked to current policy where applicable. Key Policy Areas are expanded on in Appendix 6.

Individuals with autism and their families do not constitute a uniform demographic group within standard surveys designed to capture information on employment, poverty and deprivation, and as such, autism-specific information is lacking for a number of benchmarks. Recommendations are included in the relevant sections.

1 POVERTY AND DEPRIVATION

<p>BASELINE¹⁰</p>	<p>37% of families of primary school aged children with autism experience deprivation (as defined by greater uptake of free school meals) and live in deprived areas compared to approx. 30% of families in the general population;</p> <p>Approx. 30% of the parents of children with autism are unemployed compared to approx. 6.3% of general population;</p> <p>Families of children with autism are 9%-18% worse off financially than other families.</p>
<p>BENCHMARK</p>	<p>Deprivation should be no greater than in general population;</p> <p>Unemployment ¹¹ should be no greater than for other disability groups, better still, no greater than the general population;</p> <p>Financial income should be same as families not affected by ASD.</p>
<p>RECOMMEND</p>	<p>Ensure equal pay and equal employment opportunities, which may require additional supported employment resources;</p> <p>Make available good early years childcare tailored for children with ASD and early intensive behaviour analysis-based intervention;</p> <p>Ensure all families can obtain a Benefit Check (e.g., currently available through NAAAS¹² for adults with autism and their carers).</p>
<p>POLICY LINKS</p>	<p>Autism Strategy, Supporting People, Delivering Social Change, Towards a Childcare Strategy- Bright Start, Disability Strategy.</p>

¹⁰ Source: BASE Project Vol. 3.

¹¹ NB: Employment data do not currently include autism specific information and this is necessary to monitor agreed key actions within the Autism Strategy and Action Plan and related policy areas.

¹² Northern Adult Autism Advice Service provided by the Northern Health and Social Care Trust, for evaluation see Dillenburger and McKerr (2015).

2 COST OF AUTISM

BASELINE ¹³	Cost of autism between £0.9 and £1.5mill. per lifetime; Child rearing cost up to 6 times higher than other families.
BENCHMARK	Cost of autism to be reduced by 50% (see Case Study 2); Child rearing cost reduced to same level as for other children.
RECOMMEND	<p>Commission comprehensive cost-savings analysis of diagnosis, early behaviour analysis-based interventions, and other services;</p> <p>Make available (or outsource) early diagnosis and early behaviour analysis-based interventions to reduce long-term/adult care costs;</p> <p>Make available (or outsource) evidence-based interventions (i.e., functional behaviour assessment¹⁴) to reduce challenging behaviours (such as self-harm, social withdrawal or anger management issues) and increase quality of life for families affected by ASD;</p> <p>Provide autism-specific training and funding for childcare providers;</p> <p>Compensate for extra costs incurred through personal budgets, direct payments and other benefits</p> <p>Provide information on support to meet additional cost, special equipment, transport etc. which may be available through Tax Credits and Universal Credit.</p>
POLICY LINKS	Autism Strategy, RASDN Care Pathways, Disability Strategy, Towards a Childcare Strategy- Bright Start, Improving Children’s Life Chances, Transforming Your Care.

¹³ Source: BASE Project Vol. 1.

¹⁴ NICE, 2015

3 AUTISM AWARENESS

<p>BASELINE¹⁵¹⁶</p>	<p>82% of the population in NI are aware of autism; 51% of the population know someone with autism personally; 50% of 11 -year olds and 80% of 16-year olds are aware of autism.</p>
<p>BENCHMARK</p>	<p>Good public and professional knowledge of strengths and challenges experienced by persons with ASD; Good public and professional knowledge and clarity about international best practice re interventions; Good level of awareness and knowledge among children and young people.</p>
<p>RECOMMEND</p>	<p>Continue existing awareness raising initiatives (e.g., World Autism Awareness Day), but there is no need for a new large scale general awareness raising campaign; Focus autism awareness training on frontline groups, e.g., general practitioners, health visitors, and first responders (emergency services); where good practice in related fields (e.g learning disability services¹⁷) exists, this should be referenced; Focus on raising knowledge about evidence-based interventions among the public and across education, health and social care sector professions; Monitor maintenance of public awareness, (i.e., repeat NILT Survey Autism module every 5 years) and implement awareness raising campaign, if necessary; Assess and monitor children’s awareness and knowledge of autism (i.e., autism module in Kids Life and Times Survey and Young Life and Times Survey; funded by QUB 2014). Implement awareness raising campaign in schools, if necessary; Assess and monitor young people’s awareness and knowledge of autism (i.e., autism module in Young Life and Times Survey, funded by QUB 2014). Implement awareness raising campaign in FE and HE, if necessary.</p>
<p>POLICY LINKS</p>	<p>Autism Strategy, Delivering Social Change, Disability Strategy.</p>

¹⁵ Source: BASE Project Vol. 2.

¹⁶ Source: Kid’s Life and Times/Young Life and Times surveys 2014 (Dillenburger et al 2015).

¹⁷ E.g. GAIN (*Guidelines on caring for people with a learning disability in general hospital settings*)- see http://www.gain-ni.org/flowcharts/downloads/gain_learning.pdf

4 STAFF TRAINING

<p>BASELINE¹⁸</p>	<p>Lack of autism training in pre-service qualification for professionals involved in services (max. 1-4 hours of lectures);</p> <p>Post-qualifying, in-service training of professionals mainly on Level 1 (1-2 hours awareness raising);</p> <p>Very few staff trained at Level 3 (1-2 days training) or higher (e.g., University delivered autism training).</p>
<p>BENCHMARK</p>	<p>All relevant frontline staff trained to appropriate level; those directly involved with individuals with autism at least to Level 2;</p> <p>All key staff involved in co-ordination of services, diagnosis, teaching, or intervention trained to international standards, e.g., University delivered Masters level.</p>
<p>RECOMMEND</p>	<p>Include basic autism training in qualifying training for all key professions, e.g., teachers, psychologists, social workers;</p> <p>Commission cost-savings analysis for autism training to compare training level and unit costs from Higher Education and other sectors;</p> <p>In addition to training providers already mentioned in the Autism Strategy and Action Plan (e.g., DE's Middletown Centre for Autism), DEL's Higher Education autism training should be included in the Autism Strategy, future Action Plans, and training menus for staff;</p> <p>Actively engage with DEL's HE sector and other high quality research organisations in autism research, and support research-based policy decisions.</p>
<p>POLICY LINKS</p>	<p>DENI Review of SEN; Autism Strategy.</p>

¹⁸ Source: BASE Project Vol. 1 and 4.

5 AUTISM DIAGNOSIS

<p>BASELINE¹⁹</p>	<p>Across all Trusts, there are an average of 200 referrals for autism diagnosis per month; 100 diagnoses are confirmed per month; 100 referrals are placed on watch-and-wait list or discharged;</p> <p>Diagnosis waiting time exceeds 13 weeks for 43% of children²⁰; approx. 200 children are referred per month and only approx 50% (n=100) diagnosed within statutory time frame²¹;</p> <p>59% of Special Educational Needs Statement were delayed past 26 weeks;</p> <p>Adult diagnostic service is not available in all HSC Trusts.</p>
<p>BENCHMARK</p>	<p>Diagnosis (child and adult) completed in recommended 13 weeks (or less) from referral²²;</p> <p>Watch-and-wait lists reduced significantly, better still, discontinued;</p> <p>Special educational needs statement completed within 26 weeks (or 20 weeks²³) of referral, in real partnership with parents²⁴;</p> <p>Sufficient number of staff trained and available for child and adult diagnosis or sufficient outsources available for diagnosis;</p> <p>Access to adult diagnosis available in all Trusts.</p>
<p>RECOMMEND</p>	<p>Conduct cost-savings analysis of autism diagnosis and, depending on results, either internally resource diagnostic teams or outsource autism diagnosis;</p> <p>Training for health visitors about early indicators of autism which can be detected at standard developmental reviews²⁵;</p> <p>Discontinue 'watch-and-wait' policy and introduce triage system for timely autism diagnosis;</p> <p>Discontinue considering autism as necessarily 'lifelong' to offset strategies that are not ambitious to reach 'optimal outcomes';</p> <p>Adjust criteria for adult diagnosis to reflect diagnostic manual (i.e. not on subjective assessment of 'significant' levels of difficulty in daily functioning²⁶</p>
<p>POLICY</p>	<p>Autism Strategy, RASDN/HSCB, SEN Review/Code of Practice,</p>

¹⁹ Source: BASE Project Vol. 1 & 4

²⁰ Figures as of 29/09/2014: AQW 36239/11-15

²¹ (Megaw, 2015)

²² Pending a review of assessment and diagnostic pathways, Trusts to agree, 'based on their respective capacity, a maximum waiting time': AQW 38760/11-15

²³ Reducing the SEN Statementing time-scale to 20 weeks was proposed by Perry (2015). Pending approval.

²⁵ Child development checks with Health Visitors currently at 10-14 days, 6-8 weeks, 14-16 weeks, 6- 9 months, 12 months, 2-2 ½, 3 and 4+ years, plus scheduled vaccinations, where concerns can be raised (DHSSPS, 2010).

²⁶ RASDN Adult Care Pathway 2.2. 'Adults who have significant levels of difficulty in daily functioning are suitable for specialist diagnostic assessment'.

LINKS	Transforming Your Care.
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6 INTERVENTION

BASELINE ²⁷	<p>'Early intervention' services vary greatly in scope and duration across HSCTs, despite common autism Care Pathways²⁸; often equating to no more than a once-off home visit;</p> <p>No early intensive behaviour analysis-based intervention available in statutory sector;</p> <p>Nonspecific 'eclectic approach' is prevalent without supporting research evidence.</p>
BENCHMARK	<p>Early intensive behaviour analysis-based interventions available for those who need them (see Case Study 2; Autism Speaks, 2014);</p> <p>Interventions are based on functional assessment, as recommended by NICE Guidelines 170;</p> <p>Statutory sector is 'self-sufficient' with regards to early intensive behaviour analysis-based interventions, i.e. suitably qualified professionals (e.g., BCBA) are included in all autism intervention teams, as recommended by NICE Guidelines 11;</p> <p>Parental participation is always sought and valued in intervention programmes (NB, parents are at times better informed than professionals²⁹);</p> <p>Evidence-based intervention choices are fully implemented.</p>
RECOMMEND	<p><i>Cost-saving analysis</i> should be conducted for early intensive behaviour analysis-based interventions against other options (i.e., treatment as usual in NI) and results of this analysis should be implemented;</p> <p>Board Certified Behaviour Analysts (BCBA) should lead/be included in autism teams, to ensure access to/implementation of evidence-based practice and thereby reduce potential parental recourse to Tribunals;</p> <p>Ensure sufficient provision of early intensive behaviour analysis-based interventions within statutory services (BACB, 2014);</p> <p>Fully inform parents about interventions and include parents in decision making.</p>
POLICY LINKS	Autism Strategy, RASDN/HSCB, Improving Children's Life Chances, Transforming Your Care, Disability Strategy, SEN Review

²⁷ Source: BASE Project Vol. 1 & 4.

²⁸ See individual HSCT websites for full details.

²⁹ Source: BASE Project Vol. 1

7 EDUCATION

<p>BASELINE³⁰</p>	<p>50-70% children with ASD do not achieve 5 GCSEs (34% of other children);</p> <p>Children with ASD miss school 8-13 days per school year more than other children;</p> <p>20% children with ASD excluded from school (1.5% of other children);</p> <p>7-11% of children with autism experience school absenteeism; 6% of absences are unexplained or unauthorized;</p> <p>20% children with ASD bullied in school (nearly 3x more than other children);</p> <p>25% children with ASD have mental health issues (12 times more than other children);</p> <p>Most children with ASD have fewer friends than those who do not have ASD;</p> <p>Weak evidence base for current dominant 'eclectic approach' model.</p>
<p>BENCHMARK</p>	<p>Children with ASD to achieve 5 GCSEs comparable to other children;</p> <p>Children with ASD do not miss school more than other children;</p> <p>Children with ASD are not excluded from school more than other children; no informal exclusions; exclusions reduced for all children;</p> <p>Children with ASD are not bullied, at least not more than other children; bullying is reduced for all children;</p> <p>Mental health issues of children with ASD are not not more prevalent than for other children; reduced for all children;</p> <p>Children with ASD to have a 'circle of friends' programme at school as part of their Individualised Education Plans/Personal Learning Plans;</p> <p>Where appropriate, social skills interventions are specified in the Statement of Special Educational Need or the Coordinated Support Plan;</p> <p>Individually tailored educational programmes are in place, that are based on functional assessment and international best practice.</p>
<p>RECOMMEND</p>	<p>Reasonable adjustments and student support in schools should be individually assessed at similar levels to those offered at FE/HE;</p> <p>Training provided for teaching/teaching support staff to deal with specific behaviour issues as part of Continuing Professional Development;</p> <p>Teachers should be encouraged to undertake advanced training in autism and ABA to University-based Masters level;</p>

³⁰ Source: BASE Project Vol. 1 and 3

	<p>Board Certified Behaviour Analysts (BCBA) should be included in education teams;</p> <p>Parent-school communication should ensure feedback mechanisms as part of Individual Education Plans/Independent Learning Plans;</p> <p>Effective, evidence-based anti-bullying policy should be implemented;</p> <p>Peer-mediated interventions should be initiated and teaching individualised;</p> <p>Expectations and educational ambitions for children with ASD should be high;</p> <p>Attendance, attainment, and pastoral care of children with autism should be monitored in schools (e.g., through School Census).</p>
POLICY	<p>Autism Strategy; CYPSP; RASDN/HSCB; Improving Children’s Life Chances; Transforming Your Care; Disability Strategy; SEN review; Delivering Social Change; Bright Start.</p>

8 POST-SECONDARY EDUCATION AND TRAINING

BASELINE	<p>Approx. twice as many young people with ASD are Not in Education, Employment, or Training (NEET), compared to other young people (30% vs 15%)³¹;</p> <p>In FE, 0.7% of total student body are said to have autism; course completion rates were good and compare well to students without ASD (83.3% vs 84.2%); however, educational levels were lower for students with ASD than other students, i.e., essential skills vs degree courses³²;</p> <p>In HE, 0.45% of all students are said to have ASD; course completion rates were good (0.31%); students with ASD were interested in all academic subject areas³³.</p>
BENCHMARK	<p>Number of young people with ASD in NEET is no greater than for other students; NEET is reduced for all young people;</p> <p>Students with ASD successfully complete FE and HE or other recognised training courses (e.g., apprenticeships) at the same level as other students;</p> <p>Reasonable adjustments and student support are maintained at FE/HE.</p>
RECOMMEND	<p>Monitor transition planning and publish annual figures of transition team performances in relevant reports;</p> <p>Reduce number of students with ASD in NEET through increase of 'signposting' of services and transition planning to encourage student/family engagement from school Year 10 onwards;</p> <p>Increase awareness about FE and HE by disseminating information about widening participation programmes, course options, and completion rates on websites and in social media;</p> <p>Careers and Head of Year teachers should receive tailored training to increase expectations of achievement of pupils with ASD;</p> <p>Monitor provision of reasonable adjustments.</p>
POLICY LINKS	<p>Autism Strategy; Disability Strategy.</p>

³¹ Department for Education, 2012.

³² Source: BASE Project Vol. 3 (DEL 2011/2012 figures)

³³ Source: BASE Project Vol. 3 (DEL 2011/2012 figures)

9 EMPLOYMENT AND HOUSING

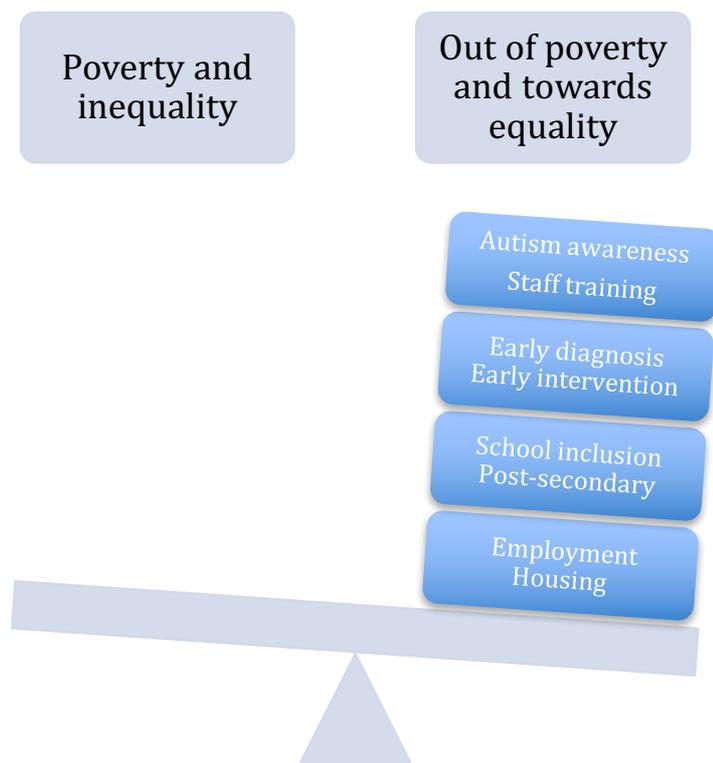
<p>BASELINE³⁴</p>	<p>Adults with ASD are employed much less frequently than other people (15% vs 94%); however, many are willing to work;</p> <p>1/3 of adults with ASD in employment are bullied;</p> <p>Most adults with ASD live with parents/family;</p> <p>Unemployment is high in families with autism (approx. 5 times higher than other families) because parents of children with autism give up employment to care for their child;</p> <p>Income in families with autism is up to 12% lower than in other families;</p> <p>Families with autism are 6 percentage points more likely to live in deprived areas than other families.</p>
<p>BENCHMARK</p>	<p>Employment rate of adults with ASD, who are considered fit for work, is similar to that of other adults with or without disabilities;</p> <p>No bullying, no abuse or assault occurs in employment or elsewhere;</p> <p>Good quality training and work placements are available to increase employment skills and maintain high levels of work motivation;</p> <p>Suitable sheltered and independent living facilities are available;</p> <p>Parents of children with ASD are enabled to stay in employment at the same rate as parents of other children.</p>
<p>RECOMMEND</p>	<p>Monitor employment rates, schemes attainments, and workplace support for adults with autism, including public/private sector internships;</p> <p>Increasing general awareness among private and public sector employers and job centre staff by building on services offered by the Employment Service;</p> <p>Increase day opportunities for adults with severe learning disabilities/mental health issues, including use of personal budgets for support and transport;</p> <p>Ensure futures planning for adults with ASD and ageing parents (e.g., as part of the Adult Care Pathway);</p> <p>Develop province-wide adult autism advice service (e.g., NAAAS model, ideally including online portal);</p> <p>Audit and monitor provision of housing and independent living services (anticipated need is significant);</p> <p>Monitor employment rates in families affected by autism and ensure other recommendations are in place to allow parents/caregivers to</p>

³⁴ Source: BASE Project Vol. 3 and 4.

	remain in or return to paid employment.
POLICY	Autism Strategy, Transforming Your Care, RASDN/HSCB, Supporting People, Disability Strategy, Enabling Success Strategy.

Figure 4 illustrates that when these benchmarks are met, the scales of poverty vs equality can be tilted in favour of individuals with ASD, i.e., out of poverty and towards equality.

Figure 4: The Poverty and Inequality (SPI) Model: Tipping the balance for autism³⁵



³⁵ The term 'Early Intervention' used in this figure is to be understood as early intensive behaviour analysis-based intervention (cf., main text)

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Appendix 1: Overview over repeated recommendations made by previous reports and policies

The ‘traffic light’ system³⁶ indicates the extent to which repeated recommendations in autism reports and policy documents (published since the Task Group Report on Autism, 2002) have been effectively implemented, according to BASE Project baseline findings (i.e., prior to the Autism Strategy, launched in Jan. 2014).

Recommendation	Appears in	Current status
Collaborative working across departments and service sectors	<ul style="list-style-type: none"> • Task Group Report on Autism (2002); • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Review of the Needs and Services for Children and Young People diagnosed with Asperger Syndrome living in Northern Ireland (2007); • Independent Review of Autism Services (2008); • Autism Strategy and Action Plan (2013-2014). 	 Policy
		 practice
Removing financing restrictions/increasing transparency between children and adult services	<ul style="list-style-type: none"> • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Independent Review of Autism Services (2008); • Autism Strategy and Action Plan (2014). 	
Service user involvement/partnership working in all developments	<ul style="list-style-type: none"> • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Meeting the needs of families living with children diagnosed with autism spectrum disorder (2007); • Independent Review of Autism Services (2008). 	
Effective, evidence-based interventions/	<ul style="list-style-type: none"> • Task Group Report on Autism (2002); • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); 	

³⁶ Appendix 1 gives an indication of implementation prior to Autism Strategy using ‘traffic light’ target indicator keys:

- *Green* denoting successful (or on target to achieve) implementation,
- *Amber* indicating partial implementation, and
- *Red* denoting absence of significant progress (cf., Health and Social Care Board [HSCB] 2012).

early intervention	<ul style="list-style-type: none"> • Meeting the needs of families living with children diagnosed with autism spectrum disorder (2007); • Review of the Needs and Services for Children and Young People diagnosed with Asperger Syndrome living in Northern Ireland (2007); • Independent Review of Autism Services (2008). 	
Improved staff training and expertise	<ul style="list-style-type: none"> • Task Group Report on Autism (2002); • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Meeting the needs of families living with children diagnosed with autism spectrum disorder (2007); • Review of the Needs and Services for Children and Young People diagnosed with Asperger Syndrome living in Northern Ireland (2007); • Independent Review of Autism Services (2008); • Autism Strategy and Action Plan (2014). 	
Improved transition processes and employment	<ul style="list-style-type: none"> • Task Group Report on Autism (2002); • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • A Review of the Needs and Services for Children and Young People diagnosed with Asperger Syndrome living in Northern Ireland (2007); • Autism Strategy and Action Plan (2014). 	
Services for adults with autism	<ul style="list-style-type: none"> • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Independent Review of Autism Services (2008); • Autism Strategy and Action Plan (2014). 	
Cost-benefit/saving assessments/audits	<ul style="list-style-type: none"> • Bamford Review of Mental Health and Learning Disability (NI) Autistic Spectrum Disorders (2006); • Meeting the needs of families living with children diagnosed with autism spectrum disorder (2007). 	

Appendix 2

BASE Project Volume 1: Comprehensive literature review

Executive summary

This comprehensive literature review was conducted in two sections. Section 1 provides a systematic review of research literature on ASD and poverty and social inclusion. Section 2 is a summary review of ASD related reports, policies, and initiatives that have been published in Northern Ireland since 2002.

Using the framework outlined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), Section 1 of the literature review focused on Autism Spectrum Disorders (ASD) and poverty. The systematic literature search (see Methods section) yielded a large increase in published papers and books regarding Autism Spectrum Disorders (ASD) in children. Section 1 showed that the literature regarding ASD in adults remains quite sparse.

There is ample evidence that early intensive behaviour interventions are linked to optimal outcomes (Ospina et al., 2008; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014), and this body of evidence has grown considerably over the past 45 years (Surgeon General, 1999). For example, in their update of Warren et al. (2011), Weitlauf et al. (2014) 'included 65 unique studies comprising 48 randomized trials and 17 nonrandomized comparative studies (19 good, 39 fair, and 7 poor quality) published since the prior review' (p.vi). These kinds of evidence-based interventions have been linked to helping the most vulnerable out of the poverty trap and reducing inequality.

Method

The literature review was conducted in two sections. For Section 1, the research literature related to individuals with ASD was reviewed using a systematic approach with regards to poverty and social inclusion. The search terms used in this review included *autism* in combination with terms such as: *employment, unemployment, further education, higher education, bullying, recreation, leisure, participation, friends, mental health, anxiety, depression, exclusion, general practitioners, awareness, and diagnosis*.

The following data banks were searched: PsychInfo, ISI Web of Knowledge, Google Scholar, and main autism specific journals; namely, *Autism, Journal of Autism and Developmental Disorders, Focus on Autism and other Developmental Disabilities, and Research in Autism Spectrum Disorders*. For the section on further and higher education a range of specialist journals were also searched (e.g. *Journal of Further and Higher Education*). Snowballing methodology was used to find further relevant literature, i.e., reference sections of papers and reports were scrutinised, autism experts and charities were asked for research publications.

Section 2 covered reviews reports and policy documents that have been published since the Task Group Report on Autism (2002) until the publication of the Autism Strategy (2013-2020). A comprehensive search of policies, strategies, and relevant reports was conducted. Sources such as statutory and commissioning bodies, voluntary organisations and academic institutions were searched as were websites

from NI government departments and bodies, such as the Equality Commission and the NI Commissioner for Children and Young People (NICCY), and youth justice policies and strategies. The search identified reports and documents related to themes of disability/ education/ health/ housing/ poverty/ social inclusion which should be relevant to individuals with ASD.

Using 'snowballing' methodology, the reference section of each report was scrutinised and any relevant reports were also included. Obviously, as well as the themes listed above, people with autism also use "core services", such as primary care and transport and therefore a category was included for "non-autism specific" reports that were relevant but did not necessarily include the search terms autism, autistic, ASD, or Asperger.

Findings

- The 'cost of autism' is estimated to be about £0.9-1.4 million across a single lifetime (depending on level of functioning);
- The total annual cost in the UK is an estimated £32 billion per year;
- Early intensive applied behaviour analysis-based interventions can lead to optimal outcomes and enhanced quality of life, potentially saving up to £1million across a single lifetime.

1. Adequate living standards

- The right to adequate living standards is a Human Right;
- The cost of bringing up a child with disabilities is 3 times that of bringing up other children;
- Employment rates are lower in families with children with ASD; often one parent gives up work to care for their child with ASD;
- A diagnosis is necessary for access to early intervention and financial benefits, yet there is a reluctance in Northern Ireland to diagnose early;
- In over half of the referrals, the diagnosis of ASD is 'deferred' for at least 12 months;
- Parents are not informed about their rights for carer assessments and other financial assistance.

2. Right to work

- Employment rates of adults with ASD are low (6-15%);
- Employment is often terminated due to lack of understanding or bullying;
- Willingness to work amongst adults with ASD is high;
- The largest cost component was parental productivity loss, representing 36% of the annual cost of autism for adults;
- Nearly half of all parents (especially mothers) of children with ASD leave work to care for their children and consequently earn 35% less than other parents;
- Families who care for someone with autism are twice as likely to have no employment-based income at all than other families;
- The main barriers to employment include challenging behaviours, difficulty finding care facilities for their sons/daughters, and concerns over losing benefits;

- Unemployment is linked to risk of mental health, lack of societal integration, criminal justice engagement, and poverty;
- Employers could enhance business by employing individuals with ASD;

3. Educational outcomes

- There is strong link between educational attainment and employment prospects;
- 5% of all children in NI have a Special Educational Needs Statement;
- 2% of all school children in NI are on the autism spectrum;
- In the UK, parents of 3.5% of 11 year-olds report having been told by a professional that their child has autism;
- About two thirds of school children with autism have a Special Educational Needs (SEN) Statement;
- 59% of SEN Statements take longer than the statutory 26 weeks;
- Stress is caused for parents by delays in receiving diagnosis and SEN Statement;
- 20% of children with autism have been excluded from school, formally or informally, (6 times more than other children) and one third of these children missed a whole school term or more;
- School exclusions have a negative impact on parents' employment status (see under Employment);
- Nearly three quarters of children with autism are at least one year behind at school, compared to one quarter of children without autism;
- While over half of all school children gain five GCSEs (graded C or above; including English and Maths), only one third to one quarter of children with autism achieve similar results, despite the fact that fewer than half of these children have co-occurring intellectual disabilities;
- In NI, children with autism do not received applied behaviour analysis-based interventions in primary or secondary school, while 44% of parents surveyed (Dillenburger et al., 2012) would prefer this form of provision for their child;
- Students with autism represent 0.7% in Further Education (FE) and 0.45% of students in Higher Education (HE);
- One third of individuals with autism aged 16 to 24 years of age are classed as 'Not in Education, Employment, or Training' (NEET), more than twice the rate of other young people;

4. Good physical and mental health

- Training of multidisciplinary professionals (including GP, Health Visitor, Social Worker) does not routinely include training in ASD;
- There are extensive ASD related policies, reports and guidelines;
- Autism awareness and knowledge about diagnosis, evidence-based interventions, and evidence-based services is low amongst GPs, social workers, and other allied professions surveyed;
- Lack of awareness and knowledge constitutes significant barriers to accessing appropriate services for individuals with autism and their families;
- The ASD related qualifications of ASD coordinators or teams is usually not specified;

- Well over half of adults with autism experience severe mental health difficulties, such as depression and anxiety;
- Physical health problems, such as vision difficulties, epilepsy and food allergy are common in individuals with autism;
- Parental stress is caused by financial worries, lack of professional support, slowness of diagnosis, dealing with challenging behaviour, and lack of information;
- Explicit policy of deferring diagnosis is controversial, especially in view of its effect on parent stress, delay of financial support for families, and postponement of early intervention;
- Siblings are anxious and concerned about their brother/sister with ASD.

5. Remove accessibility barriers

- Most individuals with autism experience difficulties with using public transport;
- Main problems include waiting at the bus stop, timetable delays, or overcrowded buses bullying, difficulty understanding timetables, sensory problems,
- Parents are worried about perceived dangers, such as running in front of a bus;
- Individuals with autism participate less in social and recreational activity than other people;
- Social communication deficits and sensory impairments are associated with low levels of participation in leisure activities; e.g., nearly half of adults with autism said that they would need support to go to the cinema;
- There is a lack of support and facilities that meet the needs of some people with autism, e.g., those with sensory difficulties or physical disabilities.

6. Appropriate housing

- Many adults with autism (25+ years of age) still live at home with their ageing parents;
- About one third of adults with autism (25+ years of age) live in residential care, one fifth live in some form of supported housing, and only very few live completely independently;
- Most ageing parents have not made plans for the future for their sons/daughters with autism;
- Nearly half of all adults with autism who live with their parents would like to live independently, however they would need suitable housing options and support with basic life skills;
- Only one in ten adults with autism has received advocacy support.

7. Participation in social and cultural life

- Children with autism find making and keeping friends difficult, some have no friends at all;
- Adults with autism also have problems making and keeping friends;
- Services that help making friends, such as befriending and social skills training, are important and are likely to provide health as well as social benefits, protect against stress and improve quality of life;

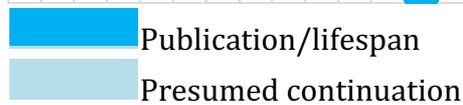
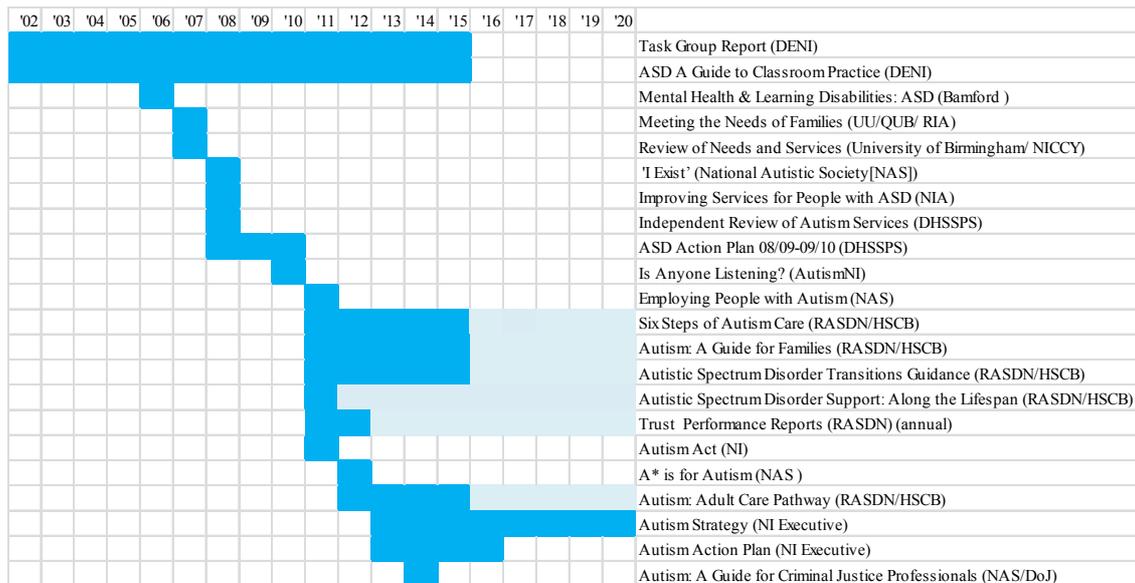
- Without sufficient support, caregivers experience isolation from leisure and community activities;
- Family functioning can be affected adversely, at times to breaking point, resulting in marital problems, and divorce;
- Respite care or short breaks for children with autism are considered supportive;
- Surveys to assess the awareness and attitudes of young people and young children towards people with autism are underway.

8. Living in safety

- Persons with disabilities are to be protected from all forms of exploitation, violence and abuse (Article 16; UNCRPD, 2006);
- Children with autism are more likely to be bullied by peers and, at times, teachers than other children;
- Bullying is less likely in special schools compared with mainstream school settings;
- Children with autism are excluded from school to protect them from being bullied;
- Bullying leads to school refusal, mental health problems (a quarter of children with autism), including anxiety, hyperactivity, self-injurious and stereotypic behaviours, and over sensitivity, self-harm or suicidal ideation (12x more than other children);
- Bullying in the workplace is common; one third of employees with autism have experienced bullying;
- Overall, 50% of adults with ASD have experienced bullying;
- 81% of adults with ASD have experienced verbal abuse and 47% have been physically assaulted.

Section 2 reviewed initiatives, reports, strategies, action plans and policies regarding ASD, or relevant for individuals with ASD published since 2002 in Northern Ireland and, where relevant, further afield. We found more than 80 relevant documents published by government departments or agencies, academic institutions and disability organisations.

Overview of NI ASD-specific initiatives and reports

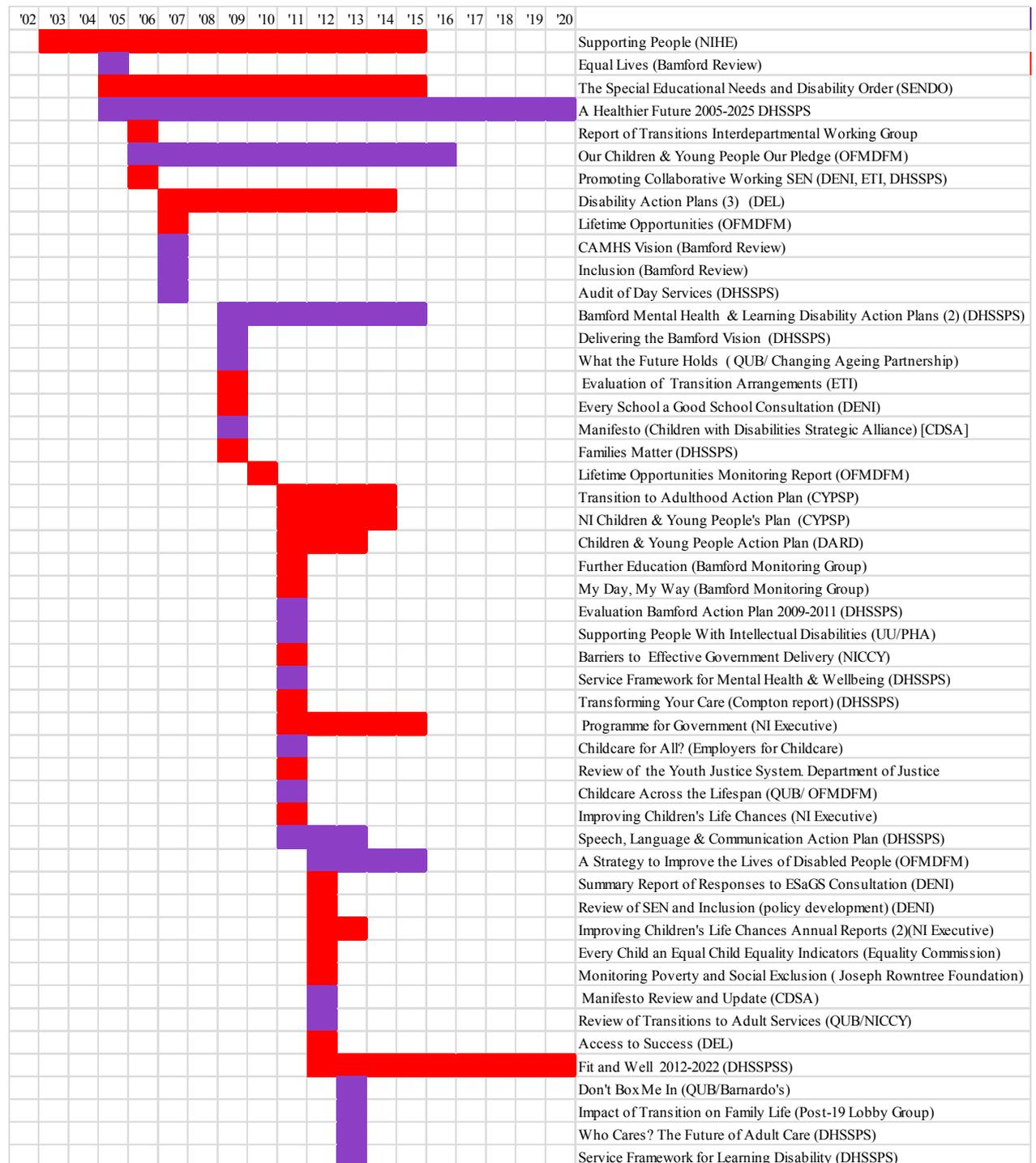


Findings from policy and strategy reports

There was an acute awareness in these reports of the shortfalls in service provision that contributed to poverty and lack of inclusion. Furthermore, lack of effective early intervention, educational underachievement, poor social and independent living skills, and limited employment support and day opportunities for those with more complex needs were identified as barriers to inclusion. Since the Task Group Report (2002), the need for improvement in the following points was repeatedly mentioned in reports and the majority were again included in the recently published Autism Strategy (2013-2020) (cf., Appendix 1).

1. Collaborative working across departments and service sectors;
2. Financing restrictions and transparency between children and adult services;
3. Service user involvement in all developments;
4. Effective, evidence-based interventions are needed (e.g., see North America);
5. Staff training and expertise (e.g., to international standards, see www.bacb.com);
6. Transition processes and employment;
7. Adults with Autism services (e.g., 'one-stop shops'; post-19 education or day opportunities);
8. Cost-benefit/saving assessment.

Other relevant NI reports



Publication/lifespan (autism references)
 Publication/lifespan (no autism references)

Appendix 3:

BASE Project Volume 2: Northern Ireland Life and Times Study

Executive summary

The primary purpose of the BASE Project was to establish how to help individuals with Autism Spectrum Disorder out of poverty by promoting social inclusion. In order to achieve this, a range of methodologies was utilised that aimed to provide a baseline against which the effect of the Autism Act (NI) 2011 and the associated Autism Strategy (2013-2020) and Action Plans can be measured. The BASE Project is reported in 5 volumes. Volume 2 reported on the analysis of the autism module of the Northern Ireland Life and Times (NILT) Survey that assessed public awareness, attitudes, knowledge, and projected behaviours with regard to individuals with ASD (all primary data and technical reports are available at www.ark.ac.uk/nilt/).

Method

The NILT (2012) survey included the first ever autism module (n=1204) to offer a baseline against which the impact of new autism legislation, policies, and strategies can be measured. The questions for the autism module focused on autism awareness, knowledge of autism, and attitudes towards individuals with autism in a variety of contexts, including social, employment, education and housing. Prior to data collection, the questions were sent to the steering group and the service user advisory group (including adults with autism, parent/caregivers, NGO) for feedback. Any comments were carefully included.

The Northern Ireland Life and Times (NILT) survey is an annual cross-sectional survey carried out by ARK, recording public attitudes to key social and political issues in Northern Ireland since 1998.

The 2012 NILT Survey was initially piloted with 60 respondents in August/September 2012. Findings of the pilot study were discussed by the whole NILT team together with the representatives from research teams responsible for each module. Very minor amendments were included in the autism module.

For participant selection, 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. Although PAF is not the only such database, it provided the most up to date and complete list of residential addresses in Northern Ireland. In each household, the adult whose next birthday was in closest proximity to the interview date was selected as participant. If the respondent was not available, the interview was re-arranged to take place at a mutually agreed time. Of the 2,350 addresses that were randomly selected, 224 proved to be vacant, derelict or commercial, leaving 2,126 eligible addresses.

Both computer assisted personal interviewing and a self-completion questionnaire were used in the survey, the latter of which was either completed by the respondent or interviewer on an iPad, or using the traditional pen and paper method if chosen

by the respondent. A total of 1,204 participants completed the main stage interviews, which equated to a response rate of 57%. Marginally fewer eligible respondents completed the self-completion questionnaire (N=1,201), resulting in a response rate of 56%. Interviews were carried out from 1st October 2012 to 10th January 2013. Subsequently, extensive range of inter- and intra-variable logic checks were carried out on the data.

Key findings:

- 82% awareness: Most people in Northern Ireland are aware of autism (n=989);
- 51% of all participants knew someone with autism personally (n=606).

Of those who were aware of autism:

- 19% had a close family member with autism (n=186), and/or a friend/acquaintance (n=296), and/or a work colleague (n=79) with autism;
- Autism awareness was particularly low for those from ethnic minorities and those with no Internet access;
- Awareness of autism specific legislation was low (20%);
- Good levels of knowledge about autism strengths and challenges, slight tendency to overestimate the occurrence of special talents;
- Prevalence of autism was underestimated (62% thought autism was much less prevalent than official figures or did not know);
- Fairly accurate perception about causes of autism, i.e., not caused by poor parenting (84%);
- Strong support for evidence-based behavioural interventions (77%), but confusion about interventions that are not evidence-based (64%);
- Strong positive attitudes towards children and adults in social, educational and employment settings;
- Autism not viewed as necessarily 'lifelong' (58%); support for independent living (78%), e.g., driving a car (83%);
- More business for employers who employ people with autism (12%);
- Strong support for families caring rather than residential care (64%);
- Confusion about service responsibility: education (26%) health (33%) or both (28%).

Given increasing prevalence rates of ASD, it is important that the general population is aware of autism and is able to respond responsibly to the associated strengths and challenges of individuals with ASD. The results of the NILT (2012) autism module show that the general public was well aware of autism, had positive attitudes, and was 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 NILT results show that a shift in focus is necessary from 'awareness raising campaigns' to an approach that delivers clarity with regard to intervention and accountability.

Appendix 4:

BASE Project Volume 3: Secondary data analysis

Executive summary

There are large existing data sets about the population in NI that had never been subjected to a secondary data analysis with regards to data on ASD. Volume 3 covered the first comprehensive secondary data analysis and thereby is available to inform future policy and practice.

Following a search of all existing, large-scale, regional or national data sets that were relevant to the lives of individuals and families affected by Autism Spectrum Disorder (ASD) in Northern Ireland, extensive secondary data analyses were carried out. The focus of these secondary data analyses was to distill any ASD related data from larger generic data sets. The findings are reported for each data set and follow a lifespan perspective, i.e., data related to children is reported first before data related to adults.

Method

A scoping exercise was carried out to identify datasets holding information on autism spectrum disorder (ASD) as well as poverty and social exclusion in Northern Ireland.

1) Data sets were identified through liaison with Statistical lead officers in:

- Office of the First Minister and Deputy First Minister (OFMDFM);
- Department of Health, Social Services and Public Safety (DHSSPS);
- Department of Education (DE);
- Department for Employment and Learning (DEL);
- Department for Regional Development (DRD);
- Department of Enterprise, Trade, and Investment (DETI);
- Department for Social Development (DSD);
- Business Services Organisation (BSO);
- Department of Culture, Arts, and Leisure (DCAL);
- Department of Environment (DOE);
- Department of Justice (DOJ);
- Police Service of Northern Ireland (PSNI).

2) Within the Department of Finance and Personnel (DFP), the following branches were contacted:

- Central Survey Unit (CSU);
- Regional Reporting and EU Programmes Branch (RREP);
- Census;
- Demography and Methodology Branch (DMB);
- Human Resource Consultancy Services (HRCS), and
- General Registrar Office (GRO).
-

3) Other data sets were searched including:

- DEL Disablement Advisory Service employment programmes and services specifically aimed at helping persons with disabilities;
- The Northern Ireland Social and Political Archive (Access, Research, Knowledge, ARK), and ARK website³⁷ ;
- The UK data service website³⁸: the 'variable and question bank' for 'autism';
- Key NI autism/disability charities and organisations, including Children with Disabilities Strategic Alliance, Disability Action, National Autistic Society, Autism NI, Autism Initiatives, Parents' Education as Autism Therapists, Middletown Centre for Autism;
- The Health and Social Care (HSC) Board of NI (for HSC Trust data).

Criteria for selecting datasets

The following inclusion/exclusion criteria were applied. Data sets had to:

- a) Contain data on autism, and autism was recorded as part of standard procedures;
- b) Hold data in relation to poverty and social exclusion;
- c) Have sufficient documentation/information available to evaluate the quality of the dataset. Where data linking was used to merge longitudinal data, the linking variables uniquely identified individuals;
- d) Have sufficient sample size to provide enough statistical power to detect a medium effect size (where statistical analysis was needed);
- e) Include Northern Ireland data within the dataset;
- f) Include data from 2003 onwards. Where more recent data existed for a particular aspect of poverty/social inclusion, this was given priority. Potential impact of changes in diagnostic practices/coding frames was made explicit in the report.

Based on these criteria the following datasets/data sources were selected:

- 1) [Millennium Cohort Study](#);
- 2) [Department of Education Primary, Post-primary and Secondary school data](#);
- 3) [Young Persons' Behaviour and Attitudes Survey 2010](#);
- 4) [Department of Education School Leavers Survey](#);
- 5) [Department for Employment and Learning Further Education data](#);
- 6) [Department for Employment and Learning Higher Education data](#);
- 7) [Department for Employment and Learning Employment Programme data](#);
- 8) [Multiple Exclusion Homelessness Survey 2010](#);
- 9) Northern Ireland Life and Times Survey 2003, 2012

³⁷ <http://www.ark.ac.uk>

³⁸ <http://discover.ukdataservice.ac.uk/variables>

Key findings:

Autism Prevalence:

Children born in 2000 in the UK,

- 0.9% (1:109) were reported to have ASD, when they were 5-years old in 2005;
- 1.8% (1:55) were reported to have ASD, when they were 7-years old in 2007;
- 3.5% (1:29) were reported to have ASD, when they were 11-year old in 2011.

Children in schools in Northern Ireland

- 1.2% of the children were reported to have ASD in 2006/07;
- 2% of the children were reported to have ASD in 2013/14.

Economic Deprivation:

- Families of children with autism (CWA) were 9%-18% worse off per week than families of children not on the autism spectrum (COA);
- Between 2006-2013 deprivation of CWA compared to COA nearly doubled as measured by eligibility for free school meals (from near 20% to 37%);
- In 2006, CWA and COA experienced similar levels of deprivation (approx. 20%). However, by 2012/13, there were notable differences with eligibility rates highest amongst children with autism, followed by children with Asperger's Syndrome, compared to COA; the respective figures of eligibility for free school meals were 36.6%, 33.1%, and 29.8%.
- Nearly 1/3 of primary school CWA lived in the most deprived areas in Northern Ireland;
- Four in ten of children with Asperger's Syndrome who attended special school lived in the most deprived areas.

Unemployment:

- Mothers of CWA were 6% less likely to be employed than mothers of COA;
- Mothers of CWA earned 35%-56% less than mothers of COA;
- CWA were 9% less likely to live in two income families than COA.

Health:

1. Pre-diagnosis, CWA were more likely than COA to have physical health problems, including walking on level ground, speech and language, hearing, eyesight, and asthma;
2. Aged 3 years of age CWA experienced poorer emotional and social health than COA, this difference increased significantly by the time they were 7 years of age;
3. Mothers of young CWA had lower levels of life satisfaction and poorer mental health than mothers of young COA.

Education:

4. In mainstream education, children with ASD aged 11-16 years reported less satisfaction with their social relationships than children without ASD (COA);

5. Younger children with ASD (aged 5 and 7 years) were less likely to enjoy school, were bullied more, and were more reluctant to attend school than COA;
6. CWA attended school 2-3 weeks less than COA;
7. Children with Asperger's Syndrome in special schools missed the equivalent of 8-13 school days more than children with Asperger's Syndrome in mainstream schools;
8. Children with ASD attending mainstream schooling were less likely to gain 5+ GCSEs A*-C or subsequently attend university.

Further and Higher Education:

9. Enrolment rates for students with ASD have risen in Further Education (FE), from 0% to 0.7%;
10. Enrolment rates for students with ASD have risen in Higher Education (HE), from 0.28% to 0.45%;
11. Students with ASD chose to study different subjects than students without ASD, although other factors, e.g., gender, age etc. may have played a part in subject selection;
12. Students with ASD from NI were more likely than students without ASD to choose Northern Irish HE Institutions rather than study outside NI.

Participation in adult life and employment:

13. A small number of adults with ASD (n=99) have benefitted from DES employment provision over the past 12 years;
14. It is unknown how many adults with ASD have received employment support elsewhere (e.g., Steps to Work).

Awareness and Attitudes in the General Population:

15. In both the 2003 and 2012 NI Life and Times Survey (NILT), NI public reported positive attitudes towards the inclusion of children with ASD in mainstream education (see also BASE Project Vol. 2).

Gap Analysis Recommendations:

This was the first comprehensive secondary analysis with regards to ASD of existing large-scale data sets in Northern Ireland. Data gaps were identified and further replications would benefit from the following data inclusion:

16. ASD should be recorded routinely in the following datasets:
 - Census;
 - Northern Ireland Survey of Activity Limitation (NISALD);
 - Training for Success/Steps to work; Steps to Success;
 - Travel survey;
 - Hate crime; and
 - Labour Force Survey.
17. Data should be collected on the destinations/qualifications of special school leavers;

18. NILT Survey autism module should be repeated in 5 years' time (2017) (see full report of 1st NILT Survey autism module 2012 in BASE Project Report Volume 2);
19. Public attitudes and awareness of children and young people have been assessed, using the Young Life and Times (YLT) Survey and the Kids Life and Times (KLT) Survey (Dillenburger et al., 2015b). These surveys should be replicated at regular intervals.

Appendix 5:

BASE Project Volume 4: Qualitative data analysis

Executive Summary

Volume 4 adds a qualitative perspective to the project by exploring the experiences of individuals with autism, their parents or carers and the staff (both public and private sector) who are tasked with supporting with service users affected by autism. Volume 4 reports on how autism policies and strategies translate into services that aim to help vulnerable individuals and their families out of the poverty trap and social exclusion.

Methods

A number of qualitative research methodologies were used:

For service providers, including health and social care professionals, educationalists, policy makers, and employers individual interviews and a number of bespoke on-line surveys were used. The online surveys were a useful way to collect data from professionals because they were anonymous, offered the opportunity to comment on aspects of professional experiences, and allowed for recommendations for service improvements without prejudice. The call for participation was sent to all Health and Social Care Trusts, Education and Library Boards, Government Departments, appropriate professional bodies, and Voluntary sector agencies (including self-advocay groups) that focus on Autism.

Interviews with employers of adults with autism facilitated a small number of in-depth case studies and examination of the factors which impacted on supported work placements and the challenges that can arise. They also allowed for suggestions for measures to increase employment opportunities in the future.

Some educationalists (n=12) participated in individual interviews.

For service users, including young people and adults with ASD and their caregivers/parents, focus groups and individual interviews were used to allow for in- depth explorations of their experiences, whether these relate to school, transition to adulthood, tertiary level education, employment, or daily living. Interviews with caregivers/parents added perspectives on service provision and also gave an insight into some of the social, emotional and economic impacts of caring for children and young people with autism. Ten students attending FE/HE institutions opted to complete an on-line survey on their experiences rather than participate in focus groups.

Prior to data collection, all surveys and interview questions were sent to the Project steering group and the service user advisory group (including adults with autism, parent/caregivers, NGO) for feedback. Any comments were carefully integrated.

Main findings

Participants

Surveys, interviews and focus groups took place with a range of key professionals (e.g., educationists, health care professionals, doctors, policy makers), individuals affected by autism, parents of children affected by autism, as well as employers of adults with autism.

Professionals (n=798), including staff from all Health and Social Care Trusts (HSCTs) and Education and Library Boards (ELBs), teachers, General Practitioners (GPs) and private and public sector employees took part in a short online survey about awareness, knowledge and training in autism. A number of these professional also took part in individual interviews.

Service user experiences were sought in individual interviews, focus groups, or surveys. This allowed individuals with autism and the parents of children and young adults with autism to outline their experiences. Eight children with autism who attended secondary school (mainstream and special schools) took part in focus groups while ten students with autism who were currently enrolled in Further and Higher Education courses completed on-line surveys. Five adults with autism, three men and two women, and fourteen parents (including two couples) of children with ASD took part in individual semi-structured interviews.

Autism awareness, knowledge, and experience of professionals, as well as autism training was established through a range of on-line surveys that established baseline levels of existing autism awareness and training levels, before resources were committed to address gaps in knowledge or training needs. Results therefore can be used by policymakers to target resources directly where there is a need to make available accurate and effective information to preparation for engaging with individuals with autism.

1.1 Professional autism awareness, knowledge, and experiences of autism training

The first Strategic Priority of the Autism Strategy and Action Plan (Northern Ireland Executive 2014, p. 51) is

‘To work in partnership with representatives from all government departments to access a range of awareness training which will support the public and private sector in providing services to people with autism, their families and carers’.

In Northern Ireland’s health, social care and education sector, post-qualifying staff training in autism is categorised at 3 levels/tiers (cf., National Autistic Society).

- Level/Tier 1 equates to brief autism awareness sessions, usually lasting no more than 1-2 hours aimed at teaching and non-teaching staff (including office staff, governors, caretakers, catering staff, drivers/ transport staff and escorts);

- Level/Tier 2 is usually a one day seminar, aimed at staff who directly support a child with autism and, for education professionals, this covers more specifically classroom based strategies and is suitable for teaching assistants, lunchtime staff and teachers;
- Level/Tier 3 commonly takes 1-2 days and aims at building on existing knowledge for staff who are taking a lead in autism provision.

In addition, advanced autism training is offered by local Universities at Undergraduate and Masters levels (e.g., MScASD at Queens University Belfast (QUB); MScABA at Ulster University (UU) and at QUB), in addition there are Open Learning courses at QUB and professional development courses at UU.

The survey results indicated the level of autism training in participants from health, social care and education sectors in Northern Ireland and therefore could be used to inform policy regarding future directions of investment in autism training.

- Half of the professionals knew someone with autism personally, consistent with NILT data showing that 50% of the general population knew someone with autism personally (BASE Report Volume 2);
- All teachers who took part in the survey had contact with children with autism, two thirds of the teachers on a daily basis, the remaining one third of teachers had less frequent contact;
- Nearly a quarter of other ELB participants had daily contact, while nearly half of ELB staff had no contact with children with autism;
- Over half of HE/FE staff respondents (57%) had no contact with individuals with autism. Only one tenth of HE/FE staff had professional contact with a student with autism on a daily basis;
- Fewer than a sixth of HSCT staff respondents had daily contact with individuals with autism, while about three in ten had no contact with individuals on the autism spectrum;
- None of the GPs who participated in this research had received any autism training through their employer;
- None of the teachers who completed the questionnaire had attended Level 3 training and only 13% had attended Level 2 'autism awareness' training;
- Only one in ten of HSCT staff questioned had received Level 2 autism training (usually lasting 1-2 days).
- Education staff participants felt that at times classroom assistants had more training in autism than teachers;
- Educational professionals who took part in the interviews generally enjoyed the 'challenge' of working with pupils with autism, and loved the 'quirkiness of their personalities'.
- Participants did not appear to be fully aware of advanced University training options in ASD and thus this resource remains potentially under-used locally.

1.2 Identification of vulnerability: Autism diagnosis and service response

The identification of those most vulnerable to poverty and social exclusion is necessary prior to any intervention. Diagnosing autism, as well as participants'

experiences with health and social service responses were assessed in interviews and focus groups. Accurate and timely diagnosis is important to allow families affected by autism to move out of the poverty trap and social exclusion because a diagnosis gives access to benefits, allows for early intervention to start building skills in the child, and consequently, for parents to maintain (or return to) employment.

Diagnosis

- Recent figures (4th quarter of 2014) show that approximately 200 referrals for an autism diagnosis are made per month (range 188-210) to HSCTs across Northern Ireland;
- Approximately 50% of these referrals lead to a full-diagnosis of autism (range 84-119 per month), with the other 50% of cases either being placed on a watch-and-wait list or discharged without a diagnosis;
- Diagnosis is important as it improve chances of better individual and parental financial, physical, and mental health;
- For the majority of parents there were clear early indications of developmental delays or other concerns about their children (cf., BASE Project Vol. 3);
- All the adults with autism who participated in the interviews recognised that they had difficulties from childhood (particularly in social situations and at school);
- Adult diagnosis can give access to educational or employment supports.

Challenges with diagnosis

- Many parents spoke of their frustration with the diagnostic process, including lengthy delays associated with getting a diagnosis and patchy professional knowledge, particularly with regards to diagnosing autism in girls;
- Parents reported problems with communication and feeling judged by professionals during the diagnostic process, e.g., they were frequently asked to repeat themselves or were not asked the right questions and left sessions feeling that important issues had not been covered;
- In addition, a small number of participants felt concerned that some professionals viewed them as 'bad' parents;
- For some participants it appeared that professionals were poorly trained or ill-informed and thus not prepared to deal with autism as it was manifested in adults, particularly when these adults were able, articulate, and had family lives.

Support

- Parents who participated in the interviews were the main caregivers for their children, providing personal and emotional care and organising social activities to a much greater extent than that which might be expected for their peers;
- Most parents reported that they had limited access to statutory services overall, but some thought that Direct Payments had provided worthwhile respite opportunities;

- The post-diagnostic support network for individuals with autism (children and adults) and their families included family, peers, self, voluntary, private and statutory sectors;
- Knowledge shared by others was thought to be very valuable; many participants belonged to parent or other peer support groups, and others used social media to seek solutions or to offer advice to others.

Challenges regarding support

- Despite the fact that early intervention is recommended and significant in securing better outcomes, very few parents received any early intervention for their children following diagnosis;
- Some parents reported that they were steered towards self-help or to the voluntary sector, because no early intervention was available in the statutory sector;
- Almost half of parents who participated had found they needed to adjust their lifestyle either by leaving employment or reducing their hours because of their caring responsibilities;
- While appreciating Disabled Living Allowance (DLA), some participants found it difficult to access as they found the forms so complex;
- Only two parents reported that they received Carer's Allowance, although the majority of participants were not in employment or worked part-time;
- Allocation of statutory support (which varies between Trusts) can have a cut-off point for individuals with an IQ above 70, which disadvantages those with learning disabilities or serious social and emotional problems whose IQ exceeds this limit;
- Parents of school leavers found that whatever support they had received discontinued once their child approached adulthood.

1.3 Education and training

Education and training are the foundations that enable vulnerable people to move out of poverty and into social inclusion. Children, students and adults with autism, and the parents of children with autism reported their experiences of education (from nursery to third level) and FE and HE training.

School and college/university experiences

- When support provision for children with autism in schools was tailored to the child's individual needs this was particularly successful;
- In general parents felt they were able to communicate effectively and comfortably with their child's school placement, if needed;
- Of the children with autism who took part in the study and who were currently attending school, most had a statement of special educational needs;

- Good communication between parents and teaching and support staff and good staff training were seen as major factors in a successful educational placement at all levels;
- Appropriate support structures and a curriculum that met individual academic demands, and peer group awareness of autism, all contributed to a good experience for students;
- The majority of parents felt their child's school placement was able to meet his or her academic needs;
- Focus group pupils identified the provision of support for individual needs and opportunities to develop new interests (or build on existing academic skills) as the main strengths in transferring to secondary education.

Addressing independent living needs

- Many professionals in both mainstream and special schools recognised the need to promote independence for individuals with autism, although some parents and school students would like to see this given greater priority;
- Educational professionals mentioned a range of activities that aimed to improve the social skills of some children with autism, such as buddy systems and links with other classes;
- Most parents felt that their child's school or college was making a positive effort to enhance social skills, although almost half believed this could be undertaken much more proactively;
- Social skills groups for school and FE/HE students can offer valuable support.

Challenges related to support needs

- Challenges at school or college included lack of staff training, lack of resources, difficulties with interacting and focusing on tasks, and lack of staff skills in dealing with students' behaviour challenges;
- Some parents had challenged Education and Library Boards (ELBs) to have specific support needs met;
- The focus on academic achievement could at times detract from teaching independent living skills;
- None of the adults with autism who participated had been diagnosed while at school, and therefore had not been supported in their school days. Overall, their school life had been very difficult in terms of engaging with staff and peers;
- A minority of parents felt that school was not meeting their child's academic needs, in part because the school was not ambitious for students with autism;
- None of the school pupils had sought or been offered careers advice from their schools, although the younger participants were aware of the provision, and expected to have some contact in the future.

Third level education and training

- School pupils who participated were looking forward to moving in to third level education, while students currently attending FE or HE institutions reported that overall it was an enjoyable experience;

- Parents whose children were attending/had attended FE/HE courses were confident the placements offered the best opportunity for their children to achieve their goals, although there was less formal support in place;
- The most commonly mentioned forms of support for respondents to the student survey included technology (such as live scribe pens, laptops and software), financial support and Asperger's tutors;
- Saturday jobs and work experience were very helpful if matched with career expectations and interests;
- The majority of respondents in the student survey felt that university/college had been a comfortable and worthwhile experience, and for many this was identified with greater independence and meeting new friends.

Challenges regarding third level education and training

- Both parents and school students reported very little engagement with transitions services;
- Adults with autism reported very unsatisfactory transitions; of the five participants, four had entered third level education but none felt prepared;
- The diminishing input of parents, who knew their sons' and daughters' individual strengths and challenges, could affect the support offered in third level education;
- Learning social skills in the real world could present challenges for students with autism.

1.4 Employment and quality of life

Service users' reports of their plans for the future offer insights into the challenges and advantages of futures and career planning, work experience and employment, and daily living and quality of life.

Futures and career planning

- As their sons and daughters grow older, parents wanted them to move into the adult world with as many opportunities as possible, building on their individual skills and interests;
- Parents hoped their children would achieve some measure of independence, living and working with as much (or as little) support as they needed but acknowledged that finding the resources and services to make this possible was likely to be difficult;
- Young people with autism were optimistic about the future, and looked forward to leaving school or college and entering adult life in a variety of careers; half of them were considering moving away from Northern Ireland.

Developing skills and gaining employment

- Work experience was perceived as useful; where this was a more significant part of the curriculum, and appropriately supported, it is likely to be more useful;
- For adult participants in employment finding the right balance of support and challenge in the workplace had been rewarding;

- For the adult participants seeking employment, undertaking further appropriate training and volunteering were seen as steps towards finding a satisfying job;
- One participant was self-employed, for which there is little statutory support, but it has been rewarding, and one in which he is fully in control of the outcomes;
- A supported work placement offered one young person with more severe disabilities further training opportunities, supported by an experienced voluntary organisation; computer training was useful and enjoyable outside the workplace;
- Two employment case studies, based on in-depth interviews with employers, showed that given suitable support systems employment does not have to be an elusive aim for adults with autism.

Barriers to employment

- Adults and young people with autism who were at school or college had received very little formal support in making career decisions;
- Parents and adults with autism recognised that gaining employment included having relevant experience, filling in application forms and taking part in interviews and therefore could be challenging even for the most able young people with autism;
- For those with learning disabilities or behaviour issues, obtaining employment or work experience was viewed as even more difficult because employers would be concerned about managing people with such problems in the workplace;
- Participants identified the major barriers to employment as lack of autism awareness and understanding both in the application process and in the workplace;
- All participant groups felt there should be more emphasis for employers on the positive aspects of autism that individuals could bring, such as attention to detail, enthusiasm, creativity and honesty.

Daily living and quality of life

- Some parents expressed concerns about the sense of responsibility which would pass on to siblings as parents aged, but all anticipated their children could move away from the family home, although they realised that this might need to be accomplished gradually;
- A number of young people in third level education and all the adults who participated were living independently;
- The great majority of participants living away from a parental home had found they could manage financially, that is, they had enough money to pay for basic needs such as food, clothing, accommodation costs and heating;
- Adults with autism who had engaged with the benefits system had mixed experiences, with some reporting very negative encounters with staff and delays in payment while others had found staff supportive at times.

Challenges in employment and daily life

- Parents realised that some of their adult sons and daughters with autism would need on-going support and mentoring as they remain vulnerable adults;
- Overall, parents felt there was a distinct lack of signposting from social services; any information they had acquired was through their own research on the internet or through contacts with parent support groups and other voluntary organisations;
- A number of parents were aware of excellent specialist provision for those with other conditions, or within other Trusts, but there seemed to be no overall regional plan for the type of accommodation which would be suitable for adults with autism;
- Adult services are at a very early stage of development with Trusts and the majority of the adult participants could not rely on the level of provision, which might be expected through Children's services. This places an additional onus on families and voluntary organisations to fill the gaps;
- Employers emphasised that employing an individual with autism demanded considerable additional time commitment from employers;
- In the short-term, employers were prepared to 'go the extra mile' to offer employment opportunities individuals with autism, however this was not feasible in the long-term without being adequately resourced.

Recommendations

The following recommendations emanated from the qualitative research findings.

Recommendations regarding diagnosis

1. Early and timely diagnosis should be made available more widely to avoid delays in intervention and benefit support for families vulnerable to poverty and social exclusion;
2. Adult diagnostic services should be available more efficiently; necessary resources should be available in all Trusts;
3. Care Pathways should include triage systems for those on the waiting list for urgent need as many intervention services are not offered until a diagnosis is obtained;
4. A more expedient solution may be to outsource triage and diagnosis to the voluntary or private sector (see Case Study of Adult Diagnostic Centre in Southampton);

Recommendations regarding training

5. Autism training should go beyond autism awareness; where appropriate for staff and carers, the focus should be on practical interventions and skills training, e.g., how to manage and support individuals with autism; this should be facilitated in-service by Boards and Trusts and by DEL through the Universities;
6. University-based autism training should be endorsed and commissioned as key qualification in autism for education and healthcare staff, and information on such courses should be widely available through employers (e.g., HSCTs, ELBs and DENI);

7. There should be more information on where to access training, for example by featuring this regularly on staff intranet/ communications;
8. In order to improve accessibility, training should be accessible on-line (e.g., Northern Health and Social Care Trust; QUB and UU courses);
9. Awareness programmes should be offered to all pupils at school to promote inclusion and reduce bullying; autism related training should be integrated during initial teacher training (ITT) (e.g., in PGCE);

Recommendations regarding education and intervention

10. Early intensive behaviour analysis-based intervention programmes should be embraced as evidence-based practice by the statutory sector; NB: although some health and education professionals already draw on behaviour analysis-based principles, for example in parent training and managing challenging behaviours, very few are trained to the international standards to deliver behaviour analysis-based, individually tailored intensive interventions; alternatively, these specialist services could be outsourced to the voluntary or private sector, although this would require additional resources.
11. Autism support groups (both for academic and social skills) should be made available in school;
12. Courses (which include peers without autism) should be made available specifically for life skills and relationship skills, preferably on school premises;
13. More flexibility for the 'spectrum' of needs; schools should avoid the predominant 'one-fits all approach', i.e., visual schedules are not needed by all children with autism;

Recommendations regarding employment and quality of life

14. Employers should be aware of, and focus on, the potential for specific skills of individuals with autism; employer specific awareness training should be promoted by DEL/DES;
15. Self-advocacy for adults with autism should be made available, i.e., ask what they want, not make decisions for them;
16. Employment support can provide job stability and enhance self-confidence, and uptake of specialist support programmes should be targeted for increase by DEL/DES;
17. Specialist groups for women with autism should be made available to offer effective support, if necessary by offering 'seed funding' and/or advice for establishing these through HSCT adult autism services;
18. Access to specialist autism counselling/advocacy service should be made available. For children this should be accessible through school referrals and on school premises where possible, and for school leavers aged 16-19 years, this should be available through the HSCT adult autism service.
19. Policy makers should listen to parents. They are the people who know what they need, but many parents who are involved in the day-to-day care of their children with autism do not have the time or energy to respond to lengthy consultation documents or join committees. Opportunities to contribute to strategies should be offered by a variety of means (including on-line forums, Twitter and Facebook) as well as the input from committed user groups organised through the Autism Strategy;

20. Personal budgets/Direct Payments should be allocated so parents/individuals with autism can plan/decide on flexible services tailored to individual need.

Appendix 6:

Key policies

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) provides the overarching policy framework for improving the lives of individuals with disabilities, their carers, and families, and indicates responsibilities for countries, departments, and agencies.

While a 'universalist' approach (i.e., meeting the needs of all, without singling out certain groups or conditions) is preferred in disability service provision (Joseph Rowntree Foundation 2011), in Northern Ireland the Autism Act (2011) and the resultant Autism Strategy (2013-2020) and first Action Plan (2013-2016), together with the lack of reliable baseline data against which to assess progress, have identified the need to focus on this particular area.

Having completed a comprehensive baseline assessment for the area of autism, the BASE Project can set a useful precedent for other key policy areas that are designed to enhance the opportunities for other disadvantaged groups.

1- Autism Strategy (2013-2020) and Action Plan (2013-2016):

Awareness – (Strategic Priorities 1 & 2). Further recommendations:

- Targeted, tailored training at Level 2 and above (provided by a range of organisations including HE) for key staff in education (including Careers and Head of Year staff in schools and colleges) and health and social care is necessary;
- Monitor levels of autism awareness through replication of NILT/KLT/YLT.

Early/Effective intervention: Children, Young People and Family (Strategic Priority 5) and **Education** (Strategic priority 8). Further recommendations:

- Conduct a comprehensive cost-savings analysis of autism services, including diagnosis and subsequent funding should be directed to evidence-based interventions.

Employment and housing -Employability (Strategic Priorities 10 & 11) and **Independence, Choice and Control** (Strategic Priority 12). Further recommendations:

- Data collection from all relevant departments and agencies should be undertaken and performance indicator figures published and reviewed annually;
- Specific responsibilities are identified in the strategic priorities but this is likely to change with the review of the current Strategy and the forthcoming (2016) departmental re-organisation.

2 - A Strategy to Improve the Lives of People with Disabilities 2011-2014 (Disability Strategy).

Although not autism-specific, a number of relevant areas and strategic priorities have been identified within this Strategy (Awareness, Early Years and Family Support, Independent Living, Standard of Living, Employment and Employability).

Awareness Raising (Strategic Priority 4) deals with the need to challenge negative perceptions and understand the diverse nature of 'disability'. Further recommendations:

- Baseline information on public and professional awareness of autism (cf BASE Volumes 2 & 4) should be considered before engaging with awareness campaigns to ensure an effective response.

Early Years and Family Support: Childcare : OFMDFM research³⁹ has indicated that less than 50% of childcare providers had the capacity to care for children with disabilities. Further recommendations:

- Bright Start (the framework of OFMDFM Childcare Strategy) identified training and support needs among providers that could be addressed by offering greater access to Level 2 autism training for childcare providers. The possibility of additional funding for childcare initiatives through *Delivering Social Change* has been identified within this framework; the availability of small grants and extra training for providers should be more widely publicised as part of the agreed 'awareness raising' campaign proposed in the Autism Strategy⁴⁰;
- A cost-savings analysis should be undertaken to determine what additional financial support is necessary to cover the costs for providers who look after children with disabilities (e.g., reduced numbers to provide adequate supervision and stimulation).

Standard of living (Strategic Priority 13): Further recommendations:

- Improved benefits uptake (lead DSD/SSA) is currently being addressed through partnership with the Northern Adult Autism Advice Services (NAAAS) in the Northern HSCT and BAAAS in the Belfast HSCT. This pilot should be fully rolled out regionally and this should include relevant data collection to monitor uptake (cf., evaluation of NAAAS by Dillenburger & McKerr, 2015).

Independent Living (Strategic Priority 14): Further recommendations:

- The need for an Independent Living programme has been identified (under Strategic Priority 8); Programme for Government targets (to be reviewed after 2015), should also include an Independent Living framework

³⁹ <http://www.ofmdfmi.gov.uk/childcare-sector-research-june-2014.pdf>

⁴⁰ AQW 41450/11-15 Through Bright Start DHSSPS have secured £500k funding to 'improve access to childcare for children with a disability' (10.02.15)

commitment.

Employment and Employability (*Strategic Priorities 15 & 16*) highlight the need for employment support and lifelong learning for individuals with disabilities (also relevant to Education/Post-Secondary Education and Training. See recommendations in Tables 7 and 8).

Supporting People. *Housing needs:[Action Plan objectives 18.1-18.5]*. Further recommendations:

- Application for supported housing/floating support already collects monitoring data (e.g, ethnicity and religious affiliation) and should include disability/specific autism monitoring information;
- An Independent Living framework (as noted in the Disability Strategy) should be incorporated and adequately signposted for service users.

Delivering Social Change [Children and Young Person's Early Action Document] *Sections 4.2 /4.5 Identifying tailored solutions based on international best practice and 5.2/5.3 Early intervention* [including DE Early Years strategy] have identified key areas relevant to BASE Project research findings on early intervention for individuals with autism, particularly in the early years. Further recommendations:

- A new programme should be initiated for early intensive behaviour analysis-based interventions for young children with autism and their parents (modelled on Case Study 2).

Additional policy links:

Transforming Your Care: Although not autism-specific, proposals **4.6 Mental Health** and **4.7 Learning Disability** (relevant to many individuals with autism) focus on how the voluntary and community sector can be involved in planning services, increasing support for carers, encouraging 'self-directed support' and personalisation of services to give individuals more choice and control; for those presently attending day centres, this should mean a shift to meaningful 'Day Opportunities' and supported employment placements (cf., examples of successful placements, including for individuals with more severe communication problems and learning disabilities, are outlined in the Case Studies in BASE Project Vol. 4).

Improving Children's Life Chances (2011-2014). The key issues associated with child poverty identified in this document have been carried forward and are reflected in the Signature Programmes of *Delivering Social Change*. While not autism specific, of particular relevance are **Strategic Priority 2**. (Support more parents to access reasonably paid work), **Strategic Priority 3**. (Ensure the child's environment supports them to thrive) and **Strategic Priority 4**. (Target financial support to be more responsive to family situations),

Children and Young People's Strategic Partnership (CYPSP) is a strategic, multi-agency partnership which has a number of relevant subgroups working to deliver

effective services. It published the *Northern Ireland Children and Young People's Plan (2011-2014)* which, although not autism-specific, contains a number of key recommendations that concur with the BASE Project recommendations.

Of particular interest is the development and evaluation of Family Support Hubs and early intervention programmes. These have the potential to deliver evidence-based early intervention programmes for children with autism, however they would have to employ Board Certified Behaviour Analysts (BCBA) in order to ensure intervention fidelity and international best practice.

The Enabling Success Strategy Department for Employment and Learning [DEL] and Department of Enterprise, Trade and Investment [DETI] 2015 has also singled out many of the issues affecting those with autism and their families as barriers to employment for disadvantaged groups in the population. It identifies not just disability but family commitments as a significant factor in economic inactivity, with three key target groups - lone parents, long-term sick and disabled individuals, and carers. For young people with disabilities, the strategy promotes intervening early in their working lives and supporting positive life choices. Further recommendations:

- While individuals with autism may not always disclose this information and in some instances individuals who are economically inactive may not engage with jobs and benefits advisors, it is a matter of concern that there is currently no record of the unemployment rate of adults of working age with autism, or of their family members. Benefits staff should record numbers of claimants of working age who have autism (or are caring for someone with autism) and this should be collated on an annual basis to allow monitoring of employment targets;
- The number of individuals with autism who are assessed as belonging to the Work Related Activity Group (WRAG) within Employment and Support Allowance (ESA) claimants should also be recorded and collated on an annual basis.

The proposed **Poverty Indicator Framework**⁴¹. Further recommendations:

- This should be expanded to include autism, either for an individual or for individuals within a family unit, as a category within the 'profile of the poor';
- The establishment of a baseline for poverty which includes autism-specific information on long-term unemployment, health and well being, educational attainment and housing indicators would be an important development and could be achieved by additions or amendments to the current surveys which contribute to poverty information, such as the Continuous Household Survey.

⁴¹ New Targeting Social Needs(TSN) Research: Poverty in Northern Ireland Summary Report <http://www.ofmdfmi.gov.uk/povertysummary.pdf>

Appendix 7

Limitations of the BASE Project

The BASE Project research built on extensive previous research conducted by members of the multidisciplinary BASE Project team. Previous projects spanned over 20 years in the field of autism research and included significant numbers of collaborations with national and international colleagues and service users from many different settings. This experience meant that some potential limitations were avoided from the outset. However, some limitations have to be acknowledged for the BASE Project.

Selection bias

As is the case in all research involving human participants, the participant samples that made themselves available in this research had to give informed consent prior to inclusion. In other words, the sample consisted only of participants who self-selected to take part.

Self-selection can lead to selection bias in two directions. First, participants may feel pressurised to participate and may therefore give responses that are not entirely open and second, the voices of those who decide not to participate are missing and the reasons for their decision not to take part cannot be established.

This limitation is not unique to the BASE Project, it affects all human research. In the BASE Project, we combated selection bias by first casting the net as widely as possible for calls for participation by including all key stakeholders such as Trusts, Board, and Departments, Voluntary Sector, NGOs, and self-advocacy groups.

Moreover, we assured potential participants that there would be no adverse consequence for participation (ie., full confidentiality was granted) or non-participation (i.e., services would not be affected in any way).

In order to prevent selection bias, the research team generally did not know the participants prior to the request to participate in the study (i.e., gatekeepers were used to disseminate the calls for participation). Therefore, it was unlikely that anyone

felt pressurised by the researchers to take part. Detailed research information sheets were included in all consent forms.

Selection bias can also be due to the timing of a survey or the location of an interview. To ensure that this was not the case in the BASE Project, all surveys were available online for many weeks and available in paper copy, if requested. There were repeated calls for participation. Interviews and focus groups were scheduled and located to suit the participants (i.e., interviews took place across the whole of NI).

Participants with autism and their caregivers are generally viewed as a 'hard to reach' research populations, with resultant issues around recruitment (Shaghghi et al., 2011). Consequently, 'Patient and Public Involvement' (PPI) plays a particularly important part in the research process. The BASE Project Stakeholder Advisory Committee was convened that included caregivers, voluntary sector, and the gatekeepers of large internet-based self-advocacy groups. The Stakeholder Advisory Committee was used to ensure that the voices of children and adults with autism were included in the whole research process, e.g., reviewing interview and survey questions, making suggestions about research topics and design, participating in interviews and focus groups.

Sample size

Obviously, a small sample size can affect the reliability of results. In order to ensure adequate sample sizes, calls for participation in the BASE Project were disseminated repeatedly to all key stakeholders, including all Health and Social Care Trusts, Education and Library Board, Government Departments, NGOs, and self-advocacy groups.

Overall, BASE Project response rates were very good. However, in the staff survey (Vol. 4) there was some uneven distribution in the sample size, especially from the education sector and from some Health and Social Care Trusts. The relatively low response rate from school teachers (n=43) was particularly disappointing, as two-thirds of the teachers who did respond had daily contact with pupils with autism.

Therefore, while it appears that some of key stakeholders who had received the invitation to participate were able to reach more participants than others, it remains

unclear if this was due to the information not being disseminated to potential participants by the some gatekeepers or if the information reached potential participants who then decided not to take part.

In any case, conclusions or recommendations made on the basis of small sample sizes were clearly identified, tempered, or removed.

Research focus

The research focus of the 2011 OFMDFM funding call and, subsequently, the focus of the BASE Project was on *poverty* and *deprivation* and this obviously limited the research scope. There are many areas that affect individual with autism and their families apart from poverty and deprivation.

For example, family stress, family functioning, and poor parental mental health also affect families who are not experiencing poverty or deprivation. These stresses can be caused by the autism diagnosis, lack of services, or by service burden. For example, there is evidence that an autism diagnosis can either increase or decrease anxiety or tension for parents or the child (Casey et al., 2012; Goodwin et al., 2014; Munteanu & Dillenburger, 2009).

There is also evidence that intensive home-based intervention programmes may initially increase parental stress and yet there is evidence that effective interventions ameliorate family stress in the long-term (McGrew et al., 2014).

Parents tend to research issues around interventions carefully and at times are more knowledgeable and keener to learn than some professionals (Dillenburger et al., 2010). Future research should explore these issues in more detail.

Staff training and competence

While staff training levels were considered in BASE Project (Vol. 4) the research did not include an assessment of subsequent staff knowledge and competence in key areas of autism services. Clearly, 'training' is only useful if it leads to competence in the relevant areas. Simply attending a talk is not the same as being trained. Training 'evaluations' commonly are conducted post-hoc, immediately after the event and

usually focus on enjoyment and organization of the event and friendliness of the staff, who delivered the event, they seldom assess the practical implementation of the newly learned content (e.g., Beidas et al., 2014; Daniels, 2003; Fairburn & Cooper, 2011).

There is evidence that staff self-reported confidence in their knowledge in a specific area does not necessarily concur with actual skills and competence in that area in practice (Heiwe et al., 2011; Fennell & Dillenburger, 2014; McKee & Dillenburger, 2009; 2012; Upton et al., 2014). Further research should establish the real effect on practical competence levels of staff who have received training in the key areas that are germane for those involved in working with individuals on the autism spectrum and their families (e.g., ASD, mental health, sensory issues, evidence-based practice, ABA, functional assessment, and challenging behaviour).