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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 1) Literature Review

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BASE PROJECT (VOL. 1) LITERATURE REVIEW

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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

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

The BASE project aimed to provide baseline data for individuals with autism against which the effect of the Autism Act (NI) 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); and

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

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

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

This is Volume 1 and presents the *comprehensive literature review*.

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Abbreviations

AAAS - Adult Autism Advisory Service

ASD - Autistic Spectrum Disorders

CAMHS - Child and Adolescent Mental Health Services

CAP - Changing Ageing Partnership

CDC- Centers for Disease Control and Prevention

CDSA - Children with Disabilities Strategic Alliance

CYPSP - Children and Young People's Strategic Partnership

DARD - Department of Agriculture and Rural Development

DENI - Department of Education

DEL - Department of Employment & Learning

DfES - Department for Education and Skills (England)

DHSSPS - Department of Health, Social Services and Public Safety

DoJ - Department of Justice

ELB - Education and Library Board

ETI - Education and Training Inspectorate

FE - Further Education

GP - General Practitioner

HE - Higher Education

HSCB - Health and Social Care Board

NAS - National Autistic Society

NHS - National Health Service

NICCY - Northern Ireland Commissioner for Children and Young People

NICE - National Institute for Health and Clinical Excellence

NIHE - Northern Ireland Housing Executive

NISRA - Northern Ireland Statistical Research Agency

OFMDFM - Office of First Minister and Deputy First Minister

ONS - Office for National Statistics

PEAT - Parents' Education as Autism Therapists

PHA - Public Health Agency

RASDN - Regional Autism Spectrum Disorder Network

RIA - Royal Irish Academy

RoI Republic of Ireland

RQIA - Regulation and Quality Improvement Authority

SEN - Special Educational Needs

SENDO - Special Educational Needs and Disability Order

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

BASE Project Vol. 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.

Section 1

Using the framework outlined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), Section 1 of the literature review focussed on Autism Spectrum Disorders (ASD) and poverty. The systematic literature search (see Methods section) yielded a large increase, over recent years, 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 applied behaviour analytic 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.

Findings

1. Cost of autism

- 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 £1 million across a single lifetime.

2. 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; healthcare costs are between 4 and 6 times greater;
- 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.

3. 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 autism cost component was productivity loss by individuals with autism and their parents, 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 more than 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; 12% said that they are more likely to use a supermarket (i.e., a company) employing individuals with ASD than one that does not.

4. Educational outcomes

- There is strong link between educational attainment and employment prospects;
- 5% of all children in NI have a Special Educational Needs Statement, and numbers are similar across Education and Library Boards;
- 2% of all school children in NI are on the autism spectrum;
- In the UK, parents of 3.5% of 11 year-olds have 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;
- The average time taken to provide a SEN Statement is more than half a school year (22 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 a 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 a quarter of children with autism achieve these, despite the fact that fewer than half of these children have co-occurring intellectual disabilities;
- In NI, children with autism do not receive applied behaviour analysis-based interventions in primary or secondary school, while 44% of parents surveyed would prefer this form of provision for their child;
- Students with autism represent only 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 are classed as Not in Education, Employment, or Training (NEET), more than twice the rate of other young people;

5. 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 initiatives, policies and guidelines (out of the 45 that were reviewed in Section 2, a total of 27 related or referred to health and social care issues);
- Autism awareness and knowledge about diagnosis, evidence-based interventions, and evidence-based services is low amongst GPs, social workers, and other allied professions;
- 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, depression, or 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.

6. Remove accessibility barriers

- Most individuals with autism experience difficulties with using public transport;
- Main problems include waiting at the bus stop, time table delays, or overcrowded buses, being bullied, 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.

7. Appropriate housing

- Most 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 have received advocacy support.

8. 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 with making friends, such as befriending and social skills training, are important and are likely to provide health and 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, with 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.

9. 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 (for a quarter of children with autism), including anxiety, hyperactivity, self-injurious and stereotypic behaviours, and over sensitivity, self-harm or suicidal ideation (12 times more than other children);
- Bullying in the workplace is common; a 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

Section 2 reviewed reports, strategies and policies regarding ASD, or relevant to ASD, that were published since Task Group Report on Autism (Department of Education; DENI 2002) in Northern Ireland (NI) and, where relevant, further afield. Over the intervening 12 years, more than 70 relevant governmental, academic and charitable documents pre-dated the Autism Strategy (2013-2020) and Autism Action Plan (2013-2016); 45 of these, i.e., the most relevant reports and initiatives, are reviewed in detail in Section 2.

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 intensive behaviour analysis-based 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 following points were repeatedly mentioned in reports and the majority were again included in the Autism Strategy (2013-2020).

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** (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 assessments** are required.

Table 1 summarises the occurrence of these recommendations in autism-specific governmental and academic reports from 2002-2014. It also gives an indication of progress in implementation to date using ‘traffic light’ target indicator keys, with green denoting successful implementation (or on target to achieve), amber indicating partial implementation and red denoting absence of significant progress (e.g. Health and Social Care Board [HSCB] 2012b).

To date, only cross-departmental working (at policy level) can be said to have made significant progress, with the development of the Implementation Group under the Autism Strategy and Action Plan (Northern Ireland Executive 2014), although the majority of the other areas continue to be targeted either through the on-going Regional Autism Spectrum Disorder Network [RASDN] initiative (see Section 2.1.3) or the Autism Action Plan (see Section 2.6.2).

The exception to this is the pursuit of a thorough cost/benefit analysis of autism services, recommended by the Bamford Review (2006) and by Keenan et al. (2007) in their review of services for families of children with ASD. In particular, as highlighted in Section 1.2, failure to provide effective early intensive behaviour analysis-based intervention has serious lifetime economic consequences (Knapp, Romeo, & Beecham, 2009; Buescher, Cidav, Knapp, & Mandell, 2014), for the individual with autism and his or her family as well as service providers and policy makers.

Table 1: Summary of recommendations in autism-specific government and academic reports

Recommendation	Appears in	Current status
Collaborative working across departments and service sectors	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 NI (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	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	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 /early intervention	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 NI (2007) Independent Review of Autism Services (2008)	
Improved staff training and expertise	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 NI (2007) Independent Review of Autism Services (2008) Autism Strategy and Action Plan (2014)	
Improved transition processes and employment	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 NI (2007) Autism Strategy and Action Plan (2014)	
Services for adults with autism	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	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)	

Introduction

Over the past few years, the publication rate of research regarding Autism Spectrum Disorders (ASD) has risen sharply. Between 1979-2000, about 850 papers, i.e., just over 30 papers per year were published on communication and autism (Lord, 2000). In the following 10 years the number of articles more than doubled to over 2000 journal articles for early behaviour analytic intervention alone (Eldevik et al., 2009).

While autism research activity in the UK lags behind that in the US and other parts of the world, between 2007 and 2011 UK research funding amounted to almost £21 million for about 106 research projects (Pellicano, Dinsmore, & Charman, 2013). Despite this considerable investment, the topics covered by UK autism research to-date are limited and weighted heavily towards research about biological factors, the brain, and cognition of people with autism. ‘Comparatively little research in the UK is conducted on diagnosis, treatments and interventions, services, and societal issues’ (Pellicano et al., 2013, p.4).

The present literature review was conducted in two sections. For Section 1, the research literature related to individuals with ASD was systematically reviewed 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 provides a summary of reports, policies, and initiatives that have been published in NI since 2002, starting with the first major report about autism, i.e., the Task Group Report on Autism (2002) and finishing with the Autism Strategy (2013-2020).

Section 1

Review of the literature

In this section, autism is defined first and the cost of autism and interventions outlined. The remainder of this section of this literature review focuses specifically on issues of inclusion/exclusion and poverty along the framework outlined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). The eight most autism relevant UNCRPD benchmarks are:

1. Adequate living standards
2. Right to work
3. Educational outcomes
4. Good Physical and mental health
5. Remove accessibility barriers
6. Appropriate housing
7. Participation in social and cultural life
8. Living in safety

1.1. What is autism?

The two main diagnostic systems, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases (ICD-10; World Health Organisation, 1992), contain a specific category for Autism Spectrum Disorder (ASD) that is used to label pervasive developmental disorders on the basis of specific atypical behaviours in social communication and repetitive, restrictive behaviours (APA, 2013). The term ASD is used throughout this report to cover the entire spectrum defined by these manuals.

Defining behaviours of ASD vary from individual to individual; some examples are shown in Table 2. Asperger Syndrome is a diagnostic subcategory of autism spectrum disorder that is not characterised by developmentally delayed language and in most cases intellectual ability is average or above. The diagnosis of Asperger Syndrome was no longer used as a separate category in DSM-5; instead ASD is diagnosed now along 3 levels of service needs, i.e., Level 1: *Requiring Support*; Level 2: *Requiring Substantial Support*; Level 3: *Requiring Very Substantial Support* (DSM-5; APA, 2013).

While, internationally, most of the published research is based on the DSM-IV or, since 2013, the DSM-5, most practitioners in NI still use the ICD-10 (WHO, 1992).

Table 2: Examples of behaviours observed for ASD diagnosis

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

A diagnosis of autism is conferred on the basis of direct behavioural observations by the diagnosing clinicians and reports about behavioural observations from parents and professionals. Currently there are no reliable biological or neurological diagnostic indicators (APA, 2013; Filipek et al., 2000). Cognitive theories that suggest a single factor underlies autism, such as Theory of Mind, Central Coherence Theory etc., are now largely exposed as problematic and mentalistic (Boucher, 2012). For example, Bedford, Pickles, Gliga, Elsabbagh, Charman, and Johnson (2014) collected behavioural data, i.e., eye gaze attention to stimuli, in very young ‘at risk’ baby siblings of children with ASD and, in line with recent genetic and neurobiological evidence, argued in support of ‘multiple impairment models of ASD’ (p.612).

There is some evidence that autism may have a genetic origin (e.g., Szatmari et al., 2007), although evidently a large range of environmental factors play a role in pre, peri-, and post-natal development (Medical Research Council; MRC, 2001). For example, Grandjean and Landrigan (2014) linked industrial chemicals with developmental neurotoxicity, and consequently neurodevelopmental disorders such as autism, and proposed that ‘[u]ntested chemicals should not be presumed to be safe to brain development’(p.330). Thornton (2006) proposed that artificially generated electromagnetic radiation can have adverse affects on mirror neurons and thus be linked to autism. A link with harmful gastrointestinal bacteria is being investigated (Pequegnata et al., 2013). A relationship between toxins present in vaccinations and autism has been alleged and while there is evidence that no linkage exists between vaccinations and autism (DeStefano, Bhasin, Thompson, Yeargin-Allsopp, & Boyle, 2004), some of this evidence has been called in question (Goldschmidt, 2014).

Many individuals with autism have co-occurring conditions, in some cases more than one (Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004). The frequency of co-occurring epilepsy varies from 5% - 38% (Mannion, Leader, & Healy, 2013; Tuchman & Rapin, 2002). Gastro-intestinal problems are also common in people affected by autism (Ibrahim, Voigt, Katusic, Weaver, & Barbaresi, 2009; Mannion et al., 2013; Mouridsen, Isager, & Rich, 2012). Other co-occurring medical diagnoses include vision impairment, mobility difficulty, hearing impairment, Down syndrome, and cerebral palsy (Kielinen et al., 2004; Office for National Statistics [ONS], 2005). Mental health problems, depression, and anxiety, are also frequent (Stewart, 2008). About half of all individuals with autism have co-occurring intellectual disability (Baio, 2012).

Prevalence estimates for Autistic Spectrum Disorder (ASD) have been rising dramatically over the past few years. For the late 20th century, Williams, Higgins, and Brayne (2006) reported a prevalence rate of 20 per 10,000 (0.2%), although there was considerable variation between the studies included in their review. A more recent systematic review of studies published since 2000 across a wide range of countries found a median prevalence estimate for ASD of 0.62% (Elsabbagh et al., 2012) with variability of prevalence rates ranging from 0.30%-1.16%.

In the USA, the Centers for Disease Control and Prevention (CDC) found overall growing prevalence rates from 1 in 110 (CDC, 2009), to 1 in 88 (CDC, 2012), and to 1 in 50 (2%) for children (CDC, 2013). Even higher figures were reported from South Korea, where Kim et al. (2011) found evidence of an estimated a prevalence rate of 1 in 38 (2.8%).

Rising prevalence rates were confirmed for NI by the Department of Health, Social Services and Public Safety (DHSSPS) using DENI data (DHSSPS, 2014) reporting a 67% rise over the past 5 years in the school population, from 1.2% to 2%. The BASE Project Secondary Data Analysis (Volume 3) confirmed these findings. The NI School Census revealed 2% of school-aged children being diagnosed with ASD (range between 1.2%-2.3% in different Education Library Boards).

In the UK as a whole, the secondary analysis of the Millennium Cohort Study (n=18,000+ children born in 2000) exposed that prevalence rates increased significantly as the children grew older, i.e., autism prevalence was 0.9% when the children were aged 5 years (in 2005); 1.8% when the children were aged 7 years (in 2007); and 3.5% when the children were aged 11 years (in 2011) (Dillenburger, Jordan, & McKerr, 2014).

There is much debate about the factors that may underlie the increasing prevalence over time; issues that are considered in this debate include changes in the diagnostic criteria, improving accuracy of case identification, rising awareness amongst relevant professionals and parents, and actual increases in the incidence rate. Prevalence studies indicate that males outnumber females by a ratio of approximately 1 to 4. There are no differences in terms of social class or ethnicity and autism, and approximately half of individuals with ASD have 'normal' IQ (>70) (Elsabbagh, Divan, Koh & et al., 2012).

1.2. Cost of autism and intervention

The 'cost of autism' (Järbrink & Knapp, 2001) has been rising and is now estimated to be about £0.9-1.4 million across a single lifetime (depending on level of functioning) (Knapp, Romeo, & Beecham, 2009). Costs include the cost of caregiving, interventions, loss of income of individuals themselves and their caregivers. Buescher, Cidav, Knapp, and Mandell (2014) confirmed costs per lifetime in the UK to be similar to costs in the USA (\$1.4-2.5 million per lifetime).

An estimated 50-75% of individuals with autism have intellectual disability and consequently fall into the higher cost bracket, bringing the total annual cost in the UK to an estimated £32 billion per year (Buescher et al. 2014; Ganz, 2006); healthcare costs in the US are between four and six times higher for children and adolescents with autism (Shimabukuro, Grosse & Rice 2008). As Knapp (2014) points out '[a]utism is the most costly medical condition in the UK' (p.1). In NI, the Department of Education alone spent in excess of £170 million on autism specific measures, including the establishment of the Middletown Centre for Autism, in addition to other SEN investments (Northern Ireland Executive, 2014).

Recent research on long-term outcomes confirmed a statistically significant relationship between early intensive applied behaviour analysis (ABA)-based interventions and optimal outcomes for autism, including a significant reduction in ASD symptoms, such as restricted and repetitive behaviours (MacDonald et al., 201; Troyb et al., 2014) and consequently, improved employment prospects and lower adult care needs (Fein et al., 2013; Orinstein et al., 2014).

In NI, these interventions are not routinely available to families (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2012) despite the fact that self-sufficiency with regards to ABA-based interventions was identified as an important issue in the Task Group Report on Autism (DENI

2002); ‘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.’ (3.21)

Lack of early intensive behavioural interventions has been linked with extremely poor long-term outcomes (Howlin, Savage, Moss, Tempier, & Rutter, 2014) and parents have sued for damages due to lack of these kinds of intervention, e.g., in Ohio, USA, a court awarded \$142,000 in damages to a family who did not receive early intensive behaviour analysis-based intervention for their son (Kelly, 2014). In Canada, Justice Frances Kiteley of the Ontario Superior Court of Justice (2005) emphasized:

The absence of ABA means that children with autism are excluded from the opportunity to access learning, with the consequential deprivation of skills, the likelihood of isolation from society and the loss of the ability to exercise the rights and freedoms to which Canadians are entitled.

Applied behaviour analysis (ABA) is the applied branch of the science of behaviour analysis. This means that behaviour analysis-based interventions are using well researched and established behavioural principles to bring about improvements in ‘socially relevant behaviours’ (Cooper, Heron, & Heward, 2007).

ABA can be employed to achieve improvements and change in any behavioural context and is not restricted to autism interventions (Dillenburger & Keenan, 2009). However, early intensive behaviour analysis-based interventions have proven highly effective with this population, so much so that ABA-based intervention are considered established interventions (National Autism Center, 2009) and are considered ‘treatment as usual’ in most of North America and Canada (Keenan et al., 2014).

Early behaviour analysis-based interventions have been linked to significant cost savings, e.g., in Ontario cost saving estimates of \$45 million per year led to a State-wide roll-out of early ABA-based interventions (Motiwalla, Gupta, Lilly, Ungar, & Coyte, 2006). Cost savings can equate to as much as approx. £1 million per life time (Peters-Scheffer, Didden, Korzilius, & Matson, 2012).

Children with ASD can be identified as young as six months of age, e.g., eye-tracking devices can distinguish eye-fixations between 2-6 months old children with and without ASD (Grandjean & Landrigan, 2014; Jones & Klin, 2013). Early diagnosis is not only important because it allows for intervention to start very early (MacDonald et al., 2014), but also because a

diagnosis is required before a family can avail of disability or caregiver benefits (more on this in Section 1.3).

Of course these kinds of cost-savings require some level of up-front investment, although as Unumb (2013) points out, ultimately, it is not the ‘cost of treatment that should concern policy makers, it the cost of not providing treatment that should be their main concern’.

Early Intensive Behaviour Intervention (EIBI) and other behaviour analysis-based interventions are not available in NI through the statutory sector (DENI, 2002). Statutory staff are not adequately trained to supervise or deliver these kinds of interventions. Parents who wish to avail of behaviour analysis-based interventions for their children have to pay for these services privately (ABA4all, 2014; Byrne & Byrne, 2005).

Consequently, provision is vulnerable to open market forces, which has led to the view that ABA-based interventions are expensive (Freeman, 2003; Keenan, Dillenburger, Moderato, & Röttgers, 2010). The cost of ABA-based ‘shadow education’ could be avoided if these interventions were considered ‘treatment as usual’ in the UK (as is the case in the USA, Canada, and Norway; Hamad et al., 2014). In NI this would mean that ABA-based interventions would be offered free to the end user through HSCT and ELB (Dillenburger, 2012).

There still is much resistance to fully endorse ABA-based interventions in Education Boards and Trusts, that is based on misinformation about what ABA is and what it is not (Hughes, 2008; Jordan, 2001; Mattaini, 2008). The problems of censorship, category mistakes, and misrepresentation of ABA in NI have been discussed at length elsewhere and are beyond the purview of this literature review (Dillenburger & Keenan, 2009; Dillenburger, 2011; Keenan et al., 2014). Suffice it to say, that lack of staff training in the science that underpins these interventions has led to wide-spread misrepresentations in NI (Keenan et al., 2014).

1.3. 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 issues (Figure 1) that were adopted into the framework of the Anti-Poverty and Social Inclusion Strategy for NI (OFMDFM, 2006).

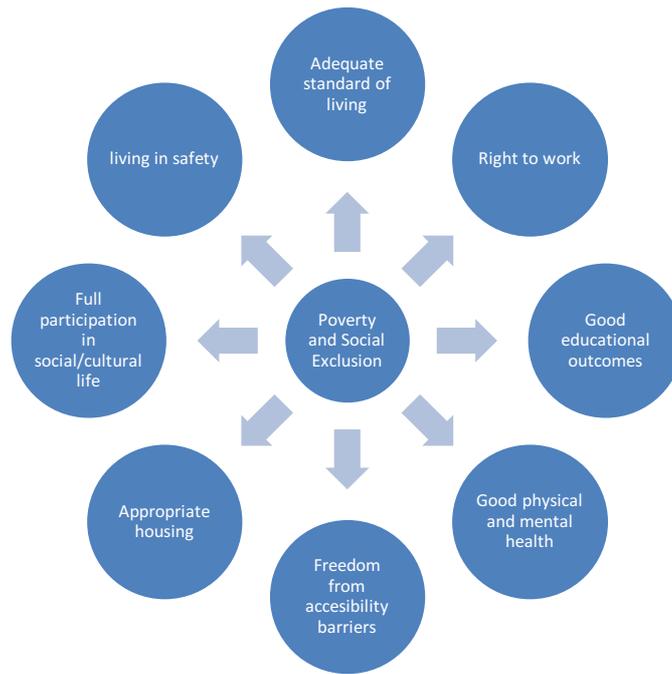


Figure 1: Rights for individuals with disabilities, including autism (UNCRPD, 2006).

The implementation of the UNCRPD is closely monitored every 5 years and each government that ratified the convention is held to account as to the effective implementation of measures to improve equality and inclusion (Pring, 2014). The UK ratified the convention in 2009.

Article 8 of the UNCRPD focuses on the importance of awareness. Issues related to autism awareness are addressed fully in BASE Project Report, Volume 2 (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013; Dillenburger, Jordan, & McKerr, 2013; Dillenburger, McKerr, Jordan, Devine, & Keenan, 2014) that reports on findings from NI Life and Times (NILT) Survey 2012 Autism Module (n=1204). Autism awareness in the general population was found to be 82% and more than half of the population (51%) knew someone with autism personally, either within their own families or in their close circle of friends. As a result, the need for general awareness raising about autism, symptoms, diagnosis, or what it means to live with someone on the spectrum has decreased. However, a recent family needs assessment (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010) found that awareness raising is still needed regarding

1. how to get financial support, what benefits individuals on the autism spectrum and their caregivers are entitled to etc.;
2. evidence-based interventions and services;

3. human rights (including UNCRC and UNCRPD);
4. stress relief and prevention of mental health problems (for parents/carers and individuals with ASD), and
5. futures planning.

The remainder of Section 1 of this literature review uses the UNCRPD framework to examine how inequality, social exclusion, and poverty affect the lives of vulnerable individuals with autism and their families. Key recommendations are outlined regarding reducing inequality and social exclusion. Section 2 then focuses on the relevant policies, strategies, and services available in NI.

1.4. Adequate living standards

The right to an adequate standard of living is enshrined in Article 25 of the Universal Declaration of Human Rights (UDHR, 1948) and establishes a minimum entitlement to food, clothing, and housing at a subsistence level. Clearly, access to adequate living standards is inexorably linked with resources availability and distribution, i.e., prosperity vs deprivation/poverty.

Arguably, poverty can be measured in many ways, ranging from very narrow income based measures (i.e., absolute poverty) to much wider measures of living standards, that are based on both income and other kinds of deprivation (i.e., relative poverty).

Inequality and social exclusion are multidimensional (Office of the First Minister and Deputy First Minister; OFMDFM, 2013) and although poverty and social exclusion often go hand in hand, some people in poverty may not be socially excluded, provided they have sufficient support networks. Similarly, not everyone who is socially excluded is necessarily in poverty.

Purely income-based measures are not suitable for measuring deprivation and poverty of individuals with disabilities and their families, because these families tend to incur greater costs to maintain an equal standard of living to their non-disabled peers (Monteith, Casement, Lloyd, & McKee, 2009). In fact, the cost of raising a child with disabilities has been estimated to be about 3 times the cost of raising a typically developing child (Järbrink, Fombonne, & Knapp, 2003) and healthcare costs have been shown to be considerably higher (between four and six times as much) for children and adolescents with autism (Shimabukuro et al. 2008). As mentioned earlier, the cost of autism approximates £0.9-1.4 million per lifetime and the vast

majority of this cost arises due to additional costs of caring and loss of income (Buescher et al., 2014). State benefits that are aimed to support individuals with disabilities and their caregivers depend on clinical diagnosis, and the reluctance in NI to diagnose ASD early (Hughes, 2014; Meekin, 2014) clearly affects the ability of these families to avail of their rights to disability or caregiver benefits, increasing the financial burden on these families. Over half of the children who are referred for an autism diagnosis either do not receive the diagnosis or are 'deferred' for at least 12 months (FOI, 2013).

Unpaid family caregivers frequently provide 50+ hours of care per week, with an estimated saving for the UK economy of in excess of £87 billion, a sum that exceeds the total expenditure on the NHS (Buckner & Yeandle, 2007). These costs arise because caring for someone with ASD often involves substantial additional expense, e.g., for support, supervision, transport, etc., and carers often feel that State benefits are not sufficient to cover these costs (Forsythe, Rahim, & Bell, 2008). In fact, carers who care fewer than 35 hours per week are not entitled to carer's allowance (National Autistic Society; NAS, 2009), even though they oftentimes give up a substantial part, if not all, of their gainful employment to perform caring duties. For those caring for more than 35 hours per week and who may have given up employment in order to be able to give the required level of care, the rate of carer's allowance in NI is £61.35 per week, which is lower than the current rate of £72.40 for jobseekers allowance for those aged 25 or over (figures sourced January 2015).

Awareness of benefits is patchy amongst individuals with autism and their carers (Forsythe et al., 2008). For example, while many parents receive disability allowance, relatively fewer get mobility allowance, direct payments, medical cards, or home tutor fees. Two thirds of the parents in Keenan, Dillenburger, Doherty, Byrne, and Gallagher's (2007) study stated that they had not been sufficiently informed by statutory services of available, much needed, financial support.

As children grow older, parental employment rates are generally expected to rise. For families of children not on the autism spectrum, the secondary data analysis of the Millennium Cohort Study (n=18,000+) showed that family employment figures rose from 82%, when the child was born (in 2000), to 86% by the time the child was 11 years old (in 2011), despite the economic downturn and rising unemployment rates that occurred during these years. In contrast for families of children with ASD, the employment rate dropped from 72%, when the child was

born, to 66% by the time the child was 11 years old (BASE Project Vol. 3; Dillenburger, Jordan, & McKerr, 2014).

In addition, families of children with ASD experience elevated divorce rates of up to 82% (National Center for Autism Research and Education, 2008); which means that approximately 1/3 of families of a child diagnosed with ASD are headed by a single parent (Bromley, Hare, Davison, & Emerson, 2004). Taken together, higher child rearing costs, unemployment, and single parenthood, result a disproportionate number of children with autism experiencing standards of living below that which would be expected in a developed country like NI.

When children with disabilities become adults and their caregivers reach retirement age problems compound as the health and caring abilities of ageing caregivers decreases. Nearly $\frac{3}{4}$ of all ageing caregivers have not made plans for the future of their adult sons/daughters with disabilities (Dillenburger & McKerr, 2011).

Barriers to inclusion in adequate living standards

The National Audit Office (NAO, 2009) revealed a number of organisational barriers to delivering effective services to individuals with autism in England. First, the structure of health and social care services made access to services and support particularly difficult for those with high functioning autism as they were eligible neither for learning disability services nor mental health services, unless they had a diagnosis of a co-occurring mental illness. Indeed, the Local Authorities in England admitted that such individuals were likely to ‘fall between the cracks’.

The DHSSPS in NI also recognised a gap in provision for individuals with autism without learning disability or mental illness (Bamford, 2005, 2006; Stewart, 2008). In order to address this issue each NI Health and Social Care Trust introduced an ASD specific team (DHSSPS, 2008). The effectiveness of these teams has not yet been evaluated.

Another organisational issue reported in England is the lack of robust data collection systems within local authorities and NHS organisations with regard to the numbers of adults with autism; e.g., fewer than 20% of local authorities and NHS partners were able to provide a precise figure for adults with low functioning autism and consequently were unable to plan appropriate services (NAO, 2009).

Awareness is not the only barrier to obtaining financial assistance. Parents in NI reported having been turned down for direct payments, not on the grounds of eligibility, but due to a lack of funding (Stewart, 2008). Job centres present accessibility difficulties for some individuals; although on a positive note, the telephone-based services are more accessible, suggesting that knowing about these services is important (Forsythe et al., 2008). The Adult Autism Advisory (AAA) Hubs that are being developed in some of the Trusts provide a ‘one-stop-shop’ for those requiring information on a range of local services. While the effectiveness of these hubs has not yet been established, evaluations are under way (Dillenburger, McKerr, & Jordan, 2014a).

Other barriers to adequate living standards relate to difficulties with the benefit application process, such as the lack of adjustments regarding potential social difficulties faced by individuals with ASD, access to information, and completing of application forms (Forsythe, et al., 2008), as well as the layout and questioning in some of the application forms (Keenan et al., 2007). If evidence from professionals, such as GPs and healthcare professionals, is required for benefit applications, problems occur when these professionals do not have appropriate autism specific training. In fact, qualifying health and social care staff training does not cover autism in any depth and in-service post-qualifying training may not address the needs of adults with autism. The vast majority of GPs in the UK believe that they need more autism specific training (NAO, 2009). A recent analysis of multidisciplinary work in autism exposed the lack of training in ASD and behavioural interventions for all health, education, and social care professionals (Dillenburger, Röttgers, Dounavi, et al., 2014).

For nearly half of all ageing parents of adult son/daughters with disabilities the greatest challenge is to provide good standard of living, keep their sons/daughters occupied, and deal with behavioural problems and skills deficits (Dillenburger & McKerr, 2009).

Reducing inequality in living standards

A carer’s assessment is an effective way of overcoming barriers to inequality and informing carers about support to which they are entitled. Yet, more than half of carers of someone with autism in England and Wales were not aware that they are entitled to a carer’s assessment (Broach, Camgöz, Heather, Owen, Potter, & Prior, 2003a). Awareness of the right to an assessment is also poor amongst carers of those with disability in NI, with one third of carers unaware or unsure about the purpose of an assessment (Dillenburger & McKerr, 2011).

Evidently, carers would find it useful to have a single point of contact for information and support, as well as help in applying for benefits (Bancroft, Batten, Lambert, & Madders, 2012).

Clearly, adequate staff training for health, social care, and education professionals would also reduce barriers to good living standards for individuals with autism and their families. Other issues related to living standards, such as employment and education, are addressed next.

1.5. Right to work

The rights of person with disabilities to gainful employment are enshrined in Article 27 of the UNCRPD (2006). The rights include a right to protection from discrimination during recruitment and on the job as well as access to appropriate vocational and in-service training. The Anti-Poverty and Social Inclusion Strategy for NI (OFMDFM, 2006) emphasises that for anyone of working age, employment is the best route out of poverty. Policy documents that are specifically aimed at getting individuals with autism and their families out of poverty and into employment are outlined in Section 2 of this review.

Official employment statistics for individuals with autism are not available in the UK, because a question on autism does not feature in employment surveys (Dillenburger, Jordan, & McKerr, 2014). Employment rates can only be disaggregated by the general category of 'disability, rather than specifically by autism. However, there is evidence that employment prospects of individuals with autism and their carers are limited and vary considerably depending on a multitude of factors, including autism specific symptoms; variations in economy across regions, countries and over time; and the nature of support being received (Howlin & Moss, 2012).

A survey of carers of adult sons/daughters with autism (n=450) found a full-time employment rate of only 6% for these adults and revealed considerable differences in full-time employment rates between adults with high functioning autism (12%) compared to adults with low functioning autism (2%) (Barnard, Harvey, Potter, & Prior, 2001). A survey of individuals with autism (n=1,179) in England indicated that only 15% of these adults were in full time employment (Rosenblatt, 2008). This survey also highlighted employment as an area for which adults with autism would like to receive more support.

These low employment rates do not reflect a lack of willingness to work. The vast majority of adults with autism want to take up paid employment (Dillenburger & McKerr, 2014). However,

many have experienced bullying or discrimination and 43% of adults with autism who have been employed left or lost their job (Bancroft et al., 2012).

Many parents of children with ASD are unemployed because they have left employment to care for their children with ASD. Parents usually do not return to employment when their children with autism grow up, due to the fact that most of them care for their sons and daughters into adulthood (Dillenburger & McKerr, 2009).

Unemployment, especially when it is long-term, is linked to health decline, increased risk to mental health, lack of societal integration, criminal justice engagement, and of course, poverty. Positive employment outcomes and reduction of benefit dependency is clearly related to achieving positive education and training outcomes, and alleviating poverty and deprivation (BASE Project Report, Volume 3).

The largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were much higher for adults than for children. (Buescher, et al., 2014, p.1)

The consequences of lost employment by individuals with autism and their parents are considerable for the individual and for the UK economy as a whole they represent 36% of the annual cost of autism for adults (Knapp et al., 2009).

Barriers to inclusion in employment

Mental health problems, medical conditions, and intellectual difficulty occur frequently in individuals with autism (Baio, 2012; Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004; Stewart, 2008), which present discernible barriers to employment. Other barriers in gaining and maintaining employment are presented in Table 3. Forsythe et al. (2008) conducted interviews and focus groups with individuals with autism, carers, autism specialists, job centre staff, transition staff, and Department for Work and Pensions (DWP) staff.

Table 3: Barriers to inclusion in employment faced by individuals with autism

Area of employment support	Barrier to employment
Transition Services	Lack of focus on employment Low rate of referral to these services
Mainstream Employment support	Not flexible enough to meet the needs of individuals with autism Needs assessment not taking social difficulties into account Exclusion of carers from the support process Placement in inappropriate jobs Employer discrimination
Specialist employment support	Lack of provision Inadequate levels of referrals to this support

Adapted from Forsythe et al. (2008)

Specialist autism services tended to be viewed positively by individuals with autism who have experienced these services. A number of aspects that were highlighted as particularly valuable included personal support with travelling, providing employers with interview techniques for those with autism, and finding suitable work. Unfortunately, too few individuals benefit from these services and many of the staff who work in transitions or mainstream employment support are not fully aware of autism. The autism specialists who were interviewed by Forsythe et al. (2008) emphasised their own training needs included adjustments to communication methods and identifying support needs despite the fact that many had undertaken autism specific training. The content of this training was not clear (Forsythe et al., 2008).

While the BASE Project Report Volume 2 identified the potential for increased business for employers that have a proactive policy of employing individuals on the autism spectrum (12% of the participants in NILT Survey stated that they would bring increased custom to such businesses) (Dillenburger, Jordan, McKerr, et al., 2013), the BASE Project Report Volume 4 includes a qualitative focus on the views and experiences of mainstream employers.

Reducing inequality in the right to work

An evaluation of the Prospects programme by Research Autism (2009) showed that both employers and employees, who used supported employment services reported positive experiences. Most employees reported job satisfaction, respect at work, and helpful on-going support, while a small proportion experienced severe problems in the workplace. Factors highlighted as unhelpful included too much customer contact, bullying, and not being understood at work.

Most employers saw the advantages of employing someone with autism and many had gained a better understanding of autism, while a sizeable minority of employers, almost three in ten, reported severe problems with employing people with autism. Overall, the research showed promising social and economic consequences of supported employment. Similar results were reported in the evaluation of a supported employment scheme in NI (Dillenburger, McKerr, & Jordan, 2014c). Further details related to employment are provided in Volume 4 of the BASE Report that includes perspectives of employees with autism in supported employment and the open market and the views of employers.

Targeted supported employment programmes show measurable benefits over generic disability employment services (Mawhood & Howlin, 1999). An eight-year follow-up of the UK-wide Prospects programme showed that the vast majority of those who had found employment in Year 1 of the program were still in jobs (Howlin, Alcock, & Burkin, 2005). While generally many of the jobs obtained by adults with autism are poorly paid and unskilled (Howlin, Goode, Hutton, & Rutter, 2004), many of the participants in the Prospects scheme obtained skilled jobs (e.g., web designer, statistician and research officer) that matched their level of ability. Individuals with severe social, linguistic or cognitive problems were also able to find appropriate employment.

Westbrook, Nye, Fong, Wan, Cortopassi, and Martin's (2012) systematic review identified only two evaluations of supported employment programmes that included rigorous research designs;

1. The Prospects programme in the UK described above (Mawhood and Howlin, 1999);
2. A study of programmes in Spain and Germany that had received less favourable evaluations (Garcia-Villamizar, Ross, & Wehman, 2000).

However, for ethical and practical reasons neither of these studies had randomly assigned the participants to the supported employment program and the control condition.

The lack of research evidence with regard to interventions to enhance employment and transition does not match the economic and social advantages of employment and the negative consequences of unemployment. This is an area in urgent need of further research.

Employers actively seeking highly skilled employees with autism

The German IT firm SAP introduced a scheme to specifically recruit individuals with autism (The Guardian, 2013) aided by Specialisterne, a Danish recruitment agency for individuals on the autism spectrum. The scheme is based on the recognition that individuals with autism could make a unique contribution in the job market because they frequently have particular skills in terms of attention to detail and accuracy in data analysis.

Specialisterne recently set up an office in Belfast. While their service remains to be fully evaluated, the demand for IT skills is expanding in NI. There are relatively few redundancies in the sector and the reliance on outsourcing low level as well as highly skilled positions due to insufficient domestic supply means that there is a potential job market for these individuals.

Employment for carers

Mothers of children affected by autism earn 35% less compared to mothers of children with a different health limitation, and 56% less than a mother of a child with no health limitation in the USA (Cidav, Marcus, & Mandell, 2012). The fathers' income was less severely affected. This is consistent with research that shows that it is usually the mother whose employment patterns are most severely affected by having a child with autism (Gray, 2003).

Although gender differences were not specifically investigated, the negative impact on employment prospects, career development, and overall financial situation for carers of children with autism was also revealed in the UK (Forsythe et al., 2008; Keenan et al., 2007). Families of children on the autism spectrum earn statistically significantly less than families of children not on the spectrum (Dillenburger, Jordan, McKerr, et al., 2014).

A large proportion of carers of children with autism in England and Wales (45%; Broach et al., 2003a) and Scotland (38%, Broach, Heather, Mustapha, Potter, & Prior, 2003b) are not in paid

employment. Compared to the families of children not on the autism spectrum, families who care for someone with autism are more than twice as likely to have no employment-based income (ONS, 2005).

The main barriers to employment faced by carers include difficulty finding care facilities to suit their needs and concerns over losing benefits (Broach et al., 2003a). Employers' understanding of caring responsibilities was highlighted as a critical factor in maintaining employment (Forsythe et al., 2008). Four in ten carers would prefer to take up employment or work longer hours if appropriate supports were provided (Broach et al., 2003a).

1.6. Educational outcomes

There is strong link between educational attainment and employment prospects; i.e., those with poor educational attainment are more likely to be unemployed, compared to those who are better educated and more skilled (OECD, 2006). If individuals with autism can fulfil their educational potential then they are less likely to experience poverty and social exclusion related problems. The UNCRPD (2006; Article 24) identifies fulfilling one's educational potential as a human right for persons with disabilities. This section will focus on this right and other related educational rights, such as not being excluded on the basis of disability, reasonable adjustments and support.

A Statement of Educational Needs (SEN Statement) is provided to children who have educational support needs. The Statement forms the basis of educational provision by setting out the target areas for the Individualised Education Plan (IEP) of each child (Table 4).

In 2013/14, a total of 2,361 children received a SEN statement in NI (0.85 % of the school age population) (Table 4). This figure constituted a 33% increase from 2009/10 when 0.64% (n=1,776) of children received a SEN Statement (increase by n=585).

The average length of time taken across all Education and Library Boards (ELB) from a request for a statutory assessment of special educational needs (SEN) to the issue of a final statement or restatement of SEN was 22 weeks and an average of 0.6 children per year were formally reassessed and provided with a new statement in each ELB between 2009-2014 (NB; data not applicable in SEELB; O'Dowd, 2014)

Table 4: Total number of school enrolments in years 1-12; with ASD; with SEN Statements; and annual statements across all five NI Education and Library Boards.

Year	2009/10	2010/11	2011/12	2012/13	2013/14
Total school enrolment	278,020	276,776	276,606	278,333	279,299
Total with ASD	3,668	4,111	4,540	4,986	5,458
Prevalence	1.32%	1.49%	1.64%	1.79%	1.95%
Total children with a SEN statement	12,570	12,796	12,938	13,271	13,818
Prevalence	4.52%	4.62%	4.68%	4.77%	4.95%
Total children with ASD & a SEN statement	2,744	2,973	3,188	3,416	3,673
Prevalence	0.99%	1.07%	1.15%	1.23%	1.32%
Total of annual new SEN statements	1,776	1,770	1,927	2,085	2,361
Prevalence	0.64%	0.64%	0.70%	0.75%	0.85%
Annual SEN Statements in ELB					
Annual SEN Statements in BELB	405	399	410	378	544
Annual SEN Statements in NEELB	341	353	420	402	410
Annual SEN Statements in SEELB	425	424	331	499	487
Annual SEN Statements in SELB	319	326	393	449	465
Annual SEN Statements in WELB	286	268	373	357	455

(Table compiled using information from O'Dowd, 2014; DHSSPS, 2014; DENI, 2014).

Appropriate intervention

People with autism and their families should receive support from a multidisciplinary group of professionals, including speech and language therapists, occupational therapists, behaviour analysts, social workers, educational psychologists, and clinical psychologists (Dillenburger, Röttgers, et al., 2014; Dounavi, 2014; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Once a diagnosis has been received there often are problems with accessing support and gaining information about services or financial help (Osborne & Reed, 2008). Stress is caused for parents by delays in receiving support after diagnosis or receiving irrelevant information (Braiden et al., 2010).

Relevant health, education, and social care professionals play an important role in providing support and facilitating independence (e.g., providing adaptation to home; respite provision). Yet, individuals with autism report mixed experiences with these professionals, and while carers usually consider services, such as respite care, social skills training, and play and leisure important, very few families are in receipt of these services (Broach et al. (2003a). In a survey of 1,000 adults with autism, the majority reported that social services did not provide them with the support they need (National Autistic Society, 2013).

School exclusions

School exclusions on the basis of disability are a major problem. In a study of 1,367 parents of children with autism, 20% said that their child had been excluded from school (Batten, Corbett, Rosenblatt, Withers, & Yuille, 2006). Amongst the children who had been excluded, a third had missed a term or more (cf., Dillenburger, Jordan, et al., 2014a). Furthermore, even though support is to be in place for excluded children after 15 days, local authorities usually failed to deliver these supports. A similar exclusion rate (27%) was reported by ONS (2005), a figure that is 6 times greater than the rate of school exclusion of pupils without autism. It appears that these exclusions are not always carried out accordance with standard procedures, as parents frequently report that their children have been excluded on an informal basis (Batten et al. 2006).

Informal exclusions have a very negative impact on parents' employment status, because these exclusions usually happen at short notice, e.g., parents are asked to pick up their child in the middle of the school day. This means that parents have to leave work unexpectedly. The timing of exclusions (e.g., they often happen just before a school trip or school inspection) raises parental suspicions that the exclusions reflected the schools inability or unwillingness to make reasonable adjustments that may be necessary to include the child in extra special activities (Treehouse, 2009).

Educational outcomes for children with autism

Educational outcomes for children with autism vary from *above average* achievement to *marked difficulty*, but in the main children with autism are more likely to have poor educational outcomes (ONS, 2005). More than 70% of children with autism are at least one year behind at school, compared to a quarter of children without autism. In addition, figures in England for 2010/11 show that while 58% of students gained five GCSEs or equivalent graded C or above (including English and mathematics), only 24% of individuals with autism achieved the same

(Department for Education; DfE, 2012a). Considering that fewer than half of the children with ASD have co-occurring intellectual disabilities (Baio, 2012), many do not fulfil their educational potential.

Apart from missing school due to high exclusion rates, children with autism frequently experience bullied and victimisation, which has been related to poor academic performance (Glew, Fan, Katon, Rivara, & Kernic, 2005) (more under Social Exclusion below). Parents in NI have expressed that the needs of their children are not adequately met as a result of insufficient parental involvement (Keenan, Dillenburger, Doherty, et al., 2010).

Educational setting for compulsory school age children

Educational outcome of children with autism depends on availability of appropriate educational settings. In the UK there are many schooling options including but not limited to mainstream, special school (autism specific), special school (not autism specific), and dual placement at special and mainstream school. Many parents do not believe that their child with autism is in the most appropriate educational setting (Batten et al. 2006; Keenan et al., 2007; Lamb, 2009). Parental dissatisfaction stems from not being given sufficient support and information when choosing a school and lack of adequate teacher training, as well as lack of educational choices at local level (Batten et al., 2006). Almost half of parents of children with autism consider moving house in order to gain access to better provision; in fact, 8% actually moved house in order to avail of more adequate services (Keenan et al., 2007).

Frequently, the type of provision identified by parents was not available, e.g., despite the fact that 44% of parents would have preferred applied behaviour analysis-based provision in primary or secondary school this is not available in NI and oftentimes, parents were ostracised by education staff for choosing ABA-based interventions for their home programmes (Keenan et al., 2007).

Further and higher education

Since 2008/09, the prevalence rate for autism in the school aged population rose from 1.2% to 2% (DHSSPS, 2014), yet only 0.7% of students in Further Education (FE) and 0.45% of students in Higher Education (HE) are recorded as being on the autism spectrum (Dillenburger, Jordan, & McKerr, 2014).

While FE and HE inclusion rates have risen over the past few years, it is difficult to know to what extent these changes reflect genuine changes in inclusion, rather than increasing disability disclosure rates. Additionally, a change in the HESA coding in 2010/11 from 'ASD' to 'Social communication/Autistic Spectrum Disorder' makes it too difficult to examine trends in Higher Education inclusion rates.

Chown and Beavan (2012) raise concerns over the lack of research on autism in Further Education (FE) and Higher Education (HE). They emphasised that there is a need for research into barriers to access, achievement rates, and preventing exclusion. With appropriate support (e.g., mentoring and advocacy) individuals with autism can achieve success in HE (NAO, 2009).

Presently in the UK, a third of individuals with autism aged 16 to 24 are classed as NEET (Not in Education, Employment, or Training) (Bancroft et al., 2012), more than twice the rate of that in the general population (Department for Education, 2012b). Similar figures were reported in the USA, where compared to many others with disabilities, young people with autism are much less likely to have any form of engagement in employment, education or training (Newman, Wagner, Knokey, Marder, Nagle, Shaver, Wei, with Cameto, Contreras, Ferguson, Greene, & Schwarting, 2011).

Barriers to inclusion in the education system

Many children with autism have co-occurring mental and physical health problems or learning difficulties (Baio, 2012; Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004; Stewart, 2008). Making appropriate adjustments to the school curriculum and environment plays a key role in children's educational outcomes. Autism specific training, beyond basic autism awareness, is particularly important for early years professionals and General Practitioners (GP) given that they are likely to be the first person parents speak to regarding their concerns about their children (Braidon, Bothwell, & Duffy, 2010).

Parents and teachers are concerned about the low levels of autism training in schools (Batten et al., 2006; Barnard, Broach, Potter, & Prior, 2002; National Foundation for Educational Research; nfer, 2011). In many cases 'training' is either non-existent or consists of a few hours that focus on cursory awareness raising rather than in-depth knowledge of interventions or supports. A recent study in England revealed that one third of teachers had not received any autism specific training at all (nfer, 2011).

Reducing inequality through improving educational outcomes

Most teachers feel that they do not have the required training to teach pupils with autism, even if they have received autism awareness training. The BASE Project survey of professionals included Northern Irish teachers, most of whom had daily contact with pupils with ASD showed that only 13% of these teachers had received more than basic Level 1 Autism Awareness training, lasting 1-2 hours (Dillenburger, McKerr, & Jordan, 2014b). This equated to training levels of the HSC staff who encountered individuals with ASD only once a fortnight/once a month, i.e., 10% of HSC staff had more than Level 1 autism training.

Awareness training commonly lacks comprehensiveness and follow-up training is not offered on a regular basis. Parents agree that without suitable training, teachers often mistake difficulties that children with autism face as challenging or non-compliant behaviour (Batten et al., 2006). At the same time, teachers who have a good understanding of autism and who make an appropriate adjustment can enhance the outcomes for children with autism.

1.7. Good physical and mental health

Persons with disabilities have the equal right to good health and the state should take appropriate action to ensure that this right is realised (Article 25; UNCRPD, 2006). The health of individuals with autism is not as good as that of individuals without autism. In addition, looking after someone with autism has detrimental effects on a caregiver's health.

Early identification and diagnosis

For persons with disability, the right to early identification and appropriate intervention (according to Article 25 of the UNCRPD, 2006) plays an important part in access to adequate living standards and, commonly, access to services and interventions is limited, particularly prior to a diagnosis of autism.

GPs are usually the first port of call for families who have concerns about their young children and therefore play an important role in making referrals for assessment and diagnosis.

Unfortunately though, despite the fact that awareness of autism has increased in the UK (Shah, 2001) and in NI now stands at 82% (Dillenburger, Jordan, McKerr, et al., 2013), the National

Autistic Society (2003) found that many practising GPs did not think they had sufficient knowledge or awareness of autism. In fact, four out of ten GPs did not feel that they had enough knowledge to assess the likelihood of ASD in a patient and a similar proportion was not aware of local sources of support and information (NAO, 2009). This clearly presents a barrier to accessing relevant information and services and may explain why parents in NI often report feeling frustrated when they try to explain to their GP that something is different about their child (Braiden et al., 2010; Keenan, Dillenburger, Doherty, et al., 2010).

The lack of awareness and knowledge about autism, diagnosis and evidence-based interventions amongst service providers, including GPs, social workers, and other allied professions constitutes another significant barrier to accessing appropriate services for individuals with autism and their families (Dillenburger, Röttgers, Dounavi, et al., 2014).

Most GPs will have received little or no training regarding ASD in their basic training, although online post-qualifying courses exist for those who want to learn about ASD (RCGP, 2014). With regard to research training, GPs will be mainly familiarised with intergroup comparison methods, such as randomised controlled trials (RCT), and thus have little knowledge of the research methodologies used to evaluate behaviour analysis-based interventions (Dounavi & Dillenburger, 2012; Keenan & Dillenburger, 2011). To guide the practice of health professionals, the National Institute for Clinical Excellence [NICE] published Clinical Guidelines:

1. Clinical guidelines for autism recognition, referral and diagnosis of children and young people (NICE, 2011);
2. Clinical guidelines for recognition, referral, diagnosis and management of adults on the autism spectrum (NICE, 2012), and
3. Clinical guidelines on autism: Management of autism in children and young people (NICE, 2013).
4. Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges. Consultation document (NICE, 2014).

It goes beyond the expectations of GPs to have read these reports or be fluent in their implementation, and most health providers have designated teams whose responsibility it is to deal specifically with ASD-related issues, although the training for ASD coordinators or teams is usually not specified (Dillenburger, Röttgers, Dounavi, et al., 2014).

Despite the regionally agreed deadlines and processes for autism diagnosis (RASDN, 2011), publicly funded diagnostic processes typically remain lengthy and cumbersome. Consequently, some parents pay for a private diagnosis that is expensive and adds further to their financial burdens and may present some quality control issues (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). According to the UNCRPD (2006) it is the government's duty to assist with disability related expenses (Article 28). However, there still is limited access to financial assistance for individuals with autism and their carers in NI due to deferred diagnosis, budgetary constraints, and an over reliance on the medical model of disability.

Barriers to inclusion in mental and physical health

In NI, many adults with autism say that a lack of support has led to severe mental health difficulties (34%), depression (57%), and anxiety (65%) (Stewart, 2008). International research suggests that anxiety disorder co-occurs more frequently in children with autism than other psychiatric disorders (Leyfer, Folstein, Bacalman, Davis, Dinh, Morgan, et al., 2006). In a review of the prevalence of anxiety in autism, prevalence rates were found to vary considerably between studies (White, Oswald, Ollendick & Scahill, 2009). MacNeil, Lopes, and Minnes (2009) propose a number of reasons why measuring anxiety in individuals with autism is so difficult; for example, mental health problems can be overlooked or difficult to distinguish from ASD related behaviours and limited verbal skills and cognitive deficits may make measurement difficult.

MacNeil et al. (2009) recommend anxiety assessments that are appropriate for use with individuals with autism. Both individuals with autism and their parents highlight that people affected by autism have many similar anxiety experiences as the general population (Ozsivadjian, Knott, & Magiati, 2012). Yet, triggers of anxiety episodes commonly are associated with specific aspects of autism such as disruptions to routines, sensory issues, difficulties with perspective taking, and conflicting social expectations. In contrast to the general population, challenging behaviours and avoidance/withdrawal were the most common anxiety related behaviours, and talking about anxiety was considered to be difficult.

Measuring mental health related issues such as anxiety and depression in individuals with autism is also difficult (Mayes, Calhoun, Murray, Ahuja & Smith, 2011). For example, social withdrawal and appetite disturbance, although typically associated with depression are also common features in autism. Therefore it is critical that practitioners are fully aware of the

differences and use carefully designed methods when measuring depression and anxiety in individuals with autism.

While a precise estimate of the prevalence of anxiety in individuals with autism does not currently exist, MacNeil's (2009) review does provide considerable evidence of elevated anxiety prevalence for individuals with autism relative to those without autism (Farrugia & Hudson, 2006; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). There is evidence that anxiety levels are higher than those found in children with other related diagnoses, e.g., language disorder (Gillott, Furniss & Walter, 2001) and conduct disorder (Green, Gilchrist, Burton & Cox, 2000). There is also some evidence of elevated prevalence of depression in individuals with autism (Kim et al., 2000; Gurney, McPheeters & Davis, 2006) although this assertion was not supported by ONS (2005).

Physical health problems, such as eyesight problems, epilepsy and food allergy are common in individuals with autism (Gurney et al., 2006; ONS, 2005), while the evidence regarding gastrointestinal problems is more mixed (Mannion et al., 2013).

In sum, high levels of mental and physical health problems lead to higher usage of health care services by people with ASD, compared to those without ASD (Gurney et al., 2006). It is particularly important, therefore, that professionals, such as GPs, are aware of specific needs of patients with ASD; they may need to alter their own professional conduct, for example, by avoiding the use of loud equipment or bright lighting (Venkat, Jauch, Russell, & Crist, 2012).

Reducing inequality in relation to mental and physical health

Parents play an important role in managing the mental and physical health problems faced by their children with ASD. This can take a considerable toll on parental emotional wellbeing and that of other children in the family (Ozsivadjian et al., 2012). Other factors, such as financial worries, fear of losing job, lack of social support, and dealing with challenging behaviour add to the stress for carers (Boyd, 2002; Bromley, Hare, Davison & Emerson, 2004; Dunn, Burbine, Bowers, & Tantleff -Dunn, 2001; Forsythe et al., 2008). There is evidence that professionals do not always identify the factors that cause most distress, a fact that adds further to parental stress (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Consequently, parents of children with autism are more likely to experience mental health problems and report higher levels of general distress compared to parents of non-disabled children (Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Montes & Halterman, 2007; ONS, 2005) or parents of children with

other disabilities, such as cystic fibrosis or learning disability (Bouma & Schweitzer, 1990; Donovan, 1988).

Most parents of children with autism experience stress in the US (Casey, Zankas, Meindl, & Parra, 2012) and in the UK (Keenan et al., 2010; Osborne & Reed, 2008). The key factors that cause stress are concerns over the diagnostic process such as the slowness, delay, and complexity of the process and for some parents, the shock of receiving a diagnosis of ASD (Braiden et al., 2010).

The development of the *Six Steps of Autism Care* (RASDN, 2011) aimed to offer a consistent approach to the diagnosis process in NI. This means that information about the assessment process and developmental interview is to be provided in advance and consequently parents should be better prepared for their child to be assessed for ASD (Nissenbaum, Tollefson & Reese, 2002). However, there still is much delay in the process, and over half of those referred for diagnosis are deferred often for over 12 months and large numbers of children remain on diagnosis waiting lists (Connolly, 2014). The 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 (Dillenburger, 2014).

As Howlin (1998) points out, reducing the problems that lead to high stress levels in carers will involve family-based support and appropriate intervention to reduce challenging behaviours in the child with autism (Howlin et al., 2014). Indeed, evidence shows that evidence-based interventions can reduce the challenging behaviours that parents consider stressful (United States Public Health Service, 1999) and that support from social, educational and health services helps to reduce parental stress (Weiss, 2002).

Support and appropriate interventions are particularly important for mothers whose health is disproportionately affected by having a child with autism, due to potential career sacrifices and the disproportionate level of caring duties (Gray, 2003). However, support is important for the whole family as parents and professionals commonly report concerns that the other children feel neglected, resent the attention given to the child with ASD, and have anxiety over their sibling's condition (Keenan et al., 2007).

1.8. Freedom from accessibility barriers

Individuals with disabilities have the same right to access to physical environment, transportation, information and communication, services as anyone else (UNCRPD, 2006; Article 9).

Barriers to inclusion due to accessibility barriers

Most individuals with autism experience difficulties with using public transport in the UK (Bancroft et al., 2012) and elsewhere, e.g., Canada (Eaves & Ho, 2008). Broach et al. (2003a) highlight that waiting at the bus stop, timetable delays, or overcrowded buses can pose barriers. Other barriers to public transport include bullying, difficulty understanding timetables, and sensory problems and anxiety and behavioural problems can lead to avoidance of public transport. Other barriers to using public transport are relatively high prevalence of mobility difficulties (Jansiewicz, Goldberg, Newschaffer, Denckla, Landa & Mostofsky, 2006; Minshew, Sung, Jones & Furman 2004; Page & Boucher 1998). Therefore, individuals with autism tend to use more expensive transport options, such as taxis or depend on lifts in privately owned cars.

For these reasons, the Disability Living Allowance (DLA) mobility component is particularly important in removing accessibility barriers for individuals with autism and their families.

Most caregivers find using public transport with individuals with autism difficult and are particularly concerned about the difficulties with perceiving dangers experienced by lower functioning individuals, i.e., a child may run in front of the bus or out on the street while the parent is paying for the ticket. This makes travelling on public transport particularly stressful for these parents.

Individuals with autism also have difficulty in accessing other aspects of the physical environment, such as going to the supermarket (Bancroft et al, 2012). Although not explicitly researched, transport and mobility difficulties are likely to contribute to these problems.

Accessing play and leisure

Children with autism participate less in social and recreational activity compared to children without autism (Hochhauser & Engel-Yeger, 2010; Solish, Perry, & Minnes, 2010); the same is true for adolescents and adults with autism (e.g., Billstedt, Gillberg & Gillberg, 2011; Orsmond,

Krauss, & Seltzer, 2004). Less play and leisure participation amongst individuals with autism may be partly due to the fact that they tend to have fewer friends (ONS, 2005) and therefore fewer people to engage in leisure activities with than people without autism.

Social and communication deficits that are indicative of the diagnosis and generally concur with social withdrawal obviously play a part in the social isolation experienced by people with autism (Orsmond et al., 2004); however, Hochhauser and Engel-Yeger (2010) found that sensory impairments were also associated with lower levels of participation in social activities; specifically, taste and smell act as a barrier for some activities, and children with movement sensitivity preferred to do things in the house.

Reducing inequality due to accessibility barriers

UK data reveal that in order to increase the participation of people affected by autism in recreational activities, more support is needed (Bancroft et al., 2012), e.g., nearly one half of adults with autism said that they would need support to go to the cinema. Most adults stated that their needs had not been assessed or met. Furthermore, there is a lack of suitable play and leisure facilities that facilitate access for those with sensory difficulties or physical disabilities (Broach et al., 2003a).

1.9. Appropriate housing

Article 19 of the UNCRPD (2006) emphasises the right of individuals with disabilities to choose their living arrangements and their place of residence, including the full range of housing provisions, such as in-home, residential, and other community support services. A survey of carers of adults with autism in NI found that, while 60% of these adults needed 24-hour support or significant daily support, 20% need some daily support, and 20% required only some weekly support or occasional support (Stewart, 2008).

Barriers to inclusion due to inappropriate housing

Most studies of individuals with autism who are living with parents, in residential care, or living semi-independently, lack the sample size needed to produce reliable estimates (Howlin & Moss, 2012), however, a larger survey in England and Wales (n=548) of members of NAS, mainly parents and carers (Broach et al., 2003a), found that most adults with autism (25+ years of age) still live at home (44%), about 33% lived in residential care, 17% in some form of supported

housing, and very few live completely independently. Only about one third of ageing carers discuss current and future housing needs with professionals (Dillenburger & McKerr, 2011).

Reducing inequality due to inappropriate housing

Nearly half of all adults with autism who live with their parents would like to live in their own home (Bancroft et al., 2012); however, they would need support with basic life skills such as paying bills, preparing meals, managing money, doing the shopping, and personal care. The degree of support needed varies considerably (Stewart, 2008). Carers consider the main barriers to independent living to be lack of appropriate housing options as well as safety, personal care and financial concerns (Broach et al., 2003a). Other barriers to independent living are the lack of accessible information and advocacy. In fact according to their caregivers, only about one in ten adults with autism has received advocacy support (Broach et al., 2003a).

1.10. Participation in social and cultural life

Persons with disabilities have the right to be included in community life (Article 19; UNCRPD, 2006) and participate in cultural life, recreation, leisure and sport (Article 30; UNCRPD, 2006) as much as anyone else; however, individuals with autism and their families are at risk of social and cultural exclusion (National Autistic Society, 2009).

Barriers to inclusion in social and cultural life

Most children with autism find making and keeping friends difficult (ONS, 2005; Dillenburger, Jordan, McKerr, & Keenan, 2014) and their parents worry that they have problems socialising, because they have few common interests with other young people. Consequently, children and young people with autism are more likely to have few or no friends when compared to children without autism or with intellectual disability (Solish et al., 2010). For example, when parents were asked if their child with autism had friends, 42% said that their child does not have any friends, in contrast, to only 1% of parents of children without autism (ONS, 2005).

Problems forming friendships have also been reported for adults with autism (Howlin et al., 2004; Stewart, 2008), although this does not reflect a lack of desire to have friends; in fact, the

vast majority of adults and children want to spend more time socialising (Stewart, 2008; Bauminger & Kasari, 2000).

Not surprisingly, carers consider services designed to aid making friends, such as befriending and social skills training, as very important. These kinds of services are likely to provide health as well as social benefits, protect against stress and improve quality of life (Price & Ladd, 1986; Geisthardt, Brotherson, & Cook, 2002). Yet, these kinds of services are not always readily available (Broach et al., 2003a).

Barriers to inclusion for carers and families of individuals with autism

Most carers of individuals with autism (over 80%) spend over 50-70 hours a week caring and consequently, they themselves have little time to engage in social and recreational activities (NAS, 2009). Without sufficient support, caregivers experience isolation not only from leisure and community activities (Bancroft et al., 2012; Keenan et al., 2007), but also from their other children, extended family and friends, and even their partners (Keenan et al., 2007). In fact oftentimes, family functioning is adversely affected in these families (Munteanu & Dillenburger, 2009; ONS, 2005) and couples can come to the breaking point, experiencing marital problems and divorce (Bancroft et al., 2012).

Reducing inequality in social and cultural life

Respite care or short breaks are considered supportive by most parents of children with autism because they offer the opportunity to concentrate on other siblings, spouses, extended family and meet other families and thus promote social inclusion for carers (Bancroft et al., 2012).

A lack of awareness amongst professionals and society in general is one factor that can lead to social exclusion of both individuals with autism and their carers. Bancroft et al. (2012) found that the vast majority of young people with autism in the UK do not think that those outside the family know enough about autism. Stewart (2008) explored what young people aged 16 and over know about autism and found that most people had heard of autism (87%); and amongst these, 79-90% were aware of key aspects of autism, such as difficulty communicating, disliking changes in routine, difficulty making sense of the world, difficulty making friends, and obsessive behaviours. Most people did not know how common autism was (90%); less than half had heard of Asperger syndrome (48%); and many held misconceptions such as, people with autism swear inappropriately (48%), were intentionally rude (24%), unable to walk (11%), were mostly children (55%) or had special abilities (62%). Even though most people said they would be

happy to work with someone with autism (83%) and were aware that people with autism have difficulty making friends, this did not mean that they actually had made an effort to reach out.

In NI, autism awareness in the general population was good (82%) and since over half of the sample knew someone with autism personally, knowledge about autism was appropriate (Dillenburger, Jordan, McKerr, et al., 2013). However, there was confusion about interventions (Dillenburger, McKerr, Jordan, Devine, & Keenan, 2014).

These findings indicate that although awareness is good in many areas, there are a number of key areas that awareness training is needed, i.e., intervention, service responsibility, and there may be a need to focus more on making people aware of how to interact with and form friendships with someone affected by autism.

Surveys to assess the awareness and attitudes of young people (Dillenburger, Schubolz, McKerr, & Jordan, 2014) and young children (Dillenburger, Lloyd, McKerr, & Jordan, 2014) are underway.

1.11. Living in safety

Article 16 of the UNCRPD (2006) emphasises the state's obligation to protect persons with disabilities from all forms of exploitation, violence and abuse. However, the majority of children with Asperger syndrome in the USA have been bullied and in fact, are four times more likely to have been bullied than typically developing children (Little, 2002). Bullying is also a major problem amongst young people with autism in the UK, where the majority of young people have been bullied at school and those with high functioning autism or Asperger syndrome are more likely to report having been bullied (Bancroft et al., 2012). Furthermore, compared to children with dyslexia, children with autism are more likely to be subjected to verbal aggression from peers (Humphrey & Symes, 2011).

Barriers to inclusion to living in safety

Bullying occurs in both verbal and physical forms and, in the school environment, parents of children with Asperger syndrome report that fellow peers and, at times teachers, are alleged of bullying (Sofronoff, Dark, & Stone, 2011).

A number of factors put those with autism at greater risk of bullying at school; for example, poor peer relationships (Delfabbro, Winefield, Trainor, Dollard, Anderson, Metzger, & Hammarstrom, 2006) indicating less peer protection; atypical interests and/or behaviours (Gray 2004); gullibility, and strong emotional and behavioural reactions to having been being bullied or teased (Sofronoff et al., 2011).

Children with Asperger syndrome who attend special schools are less likely to experience bullying than those attending mainstream settings (van Roekel, Scholte & Didden, 2010); their experience of bullying is comparable to children without autism educated in mainstream settings (Due et al., 2005). This may be because the proportion of students with ASD in special schools is relatively high and therefore the other children, and the teachers, are more accustomed to the characteristics of children with ASD (van Roekel et al., 2010).

Parents have expressed concerns about schools that appear to respond to bullying by excluding the child with autism on the grounds of safety, rather than dealing with the bully (Treehouse, 2009). Most parents whose child has been bullied at school report negative educational consequences such as the child missing or changing school, or even refusing to go to school (Batten et al., 2006).

Failure to prevent children with autism from being bullied leads to greater levels of mental health problems, including anxiety, hyperactivity, self-injurious and stereotypic behaviours, and over sensitivity (Cappadocia, Weiss & Pepier, 2012). Most parents believe that bullying causes their child to have lower self-esteem and in many cases engage in self-injurious behaviour (25%) or have suicidal ideation (12 x the rate of other children) (Batten et al., 2006; ONS, 2005).

Bullying is also common in adulthood; approximately one third of the individuals with autism who are or have been employed have been bullied in the workplace (Bancroft et al., 2012). The overall rate of bullying is 50% amongst adults with autism in NI (Stewart, 2008) and England (Rosenblatt, 2008).

Bullying is clearly related to hate crime. NAS (2013b) reported that in their survey the overwhelming majority of individuals with autism (n=approx. 800) had experienced verbal abuse (81%) and nearly half had been physically assaulted (47%), exploited or experienced theft or fraud (28%), damage to possessions or property (28%), and cyber bullying (24%). Over half (54%) of those who reported the crime said that the police did not record it as a hate crime, casting doubt over official hate crime statistics (NAS, 2013b).

Reducing inequality and living in safety

In order to deal with bullying and the associated negative consequences, Humphrey and Symes (2011) outline the need for a two pronged approach. First, they proposed to improve social skills amongst individuals with ASD; for example, schools could teach children to report bullying to the teacher rather than reacting aggressively. Improving social skills can indirectly reduce the risk of bullying by increasing peer interactions and peer awareness of ASD. Second, they proposed raising peer awareness and understanding of ASD; e.g., teaching children without ASD how to make attempts to engage with individuals with autism more explicit.

1.12 Summary

A comprehensive literature review was conducted of existing research on ASD and poverty and social inclusion. Using the framework outlined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), first, evidence was provided about outcomes and cost of diagnosis and early intensive applied behaviour analytic interventions. Then existing research was scrutinised with regards to the 8 autism related foci of the UNCRPD including *adequate living standards, right to work, educational outcomes, good physical and mental health, remove accessibility barriers, appropriate housing, participation in social and cultural life, and living in safety.*

Overall, it was found that much is known about autism and how best to support individuals on the autism spectrum and their families. Yet, this knowledge is not always routinely implemented in NI and consequently individuals with autism still experience exclusion across their lifespan. Exclusion is related to stress, bullying, and mental health issues and, ultimately, these individuals and their families miss out on education and long-term employment opportunities. Together with the relatively high costs for care, this condemns these families and individuals affected by autism to the poverty trap.

Section 2

Review of ASD reports, policies, and initiatives in Northern Ireland (2002-2014).

This section 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). The focus of many of these reports, strategies, and policy documents was on ‘helping the most vulnerable out of the poverty trap and reducing inequalities’.

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.

As well as the six major NI reports/initiatives that occurred since the publication of the Task Group Report on Autism (2002), a total of 16 reports specific to autism in NI, and 61 other reports, strategies, action plans, and initiatives that covered issues relevant to autism, poverty, wellbeing, and inclusion were identified (including 8 from elsewhere in the UK and the Republic of Ireland). The major reports and initiatives were reviewed in detail, while others were included in the reference section; the remainder of the NI reports are included in the appendices (see Figure 2 and Appendices 1 and Appendix 2).

In order to set in the context the development of the Autism Strategy (2013-2020) and Action Plan (2013-2016) (Northern Ireland Executive, 2014) discussion of the most significant reports and initiatives is arranged chronologically within each category. Mindful of the constraints of a literature review which needs to remain both informative and readable, the initiatives are

analysed individually while reports and strategies are considered briefly in the form of short annotated bibliographies (American Psychological Society, 2001) before drawing together major emerging themes.

Figure 2: NI policies, strategies, and reports relevant to individuals with ASD and their families (2002-2014).

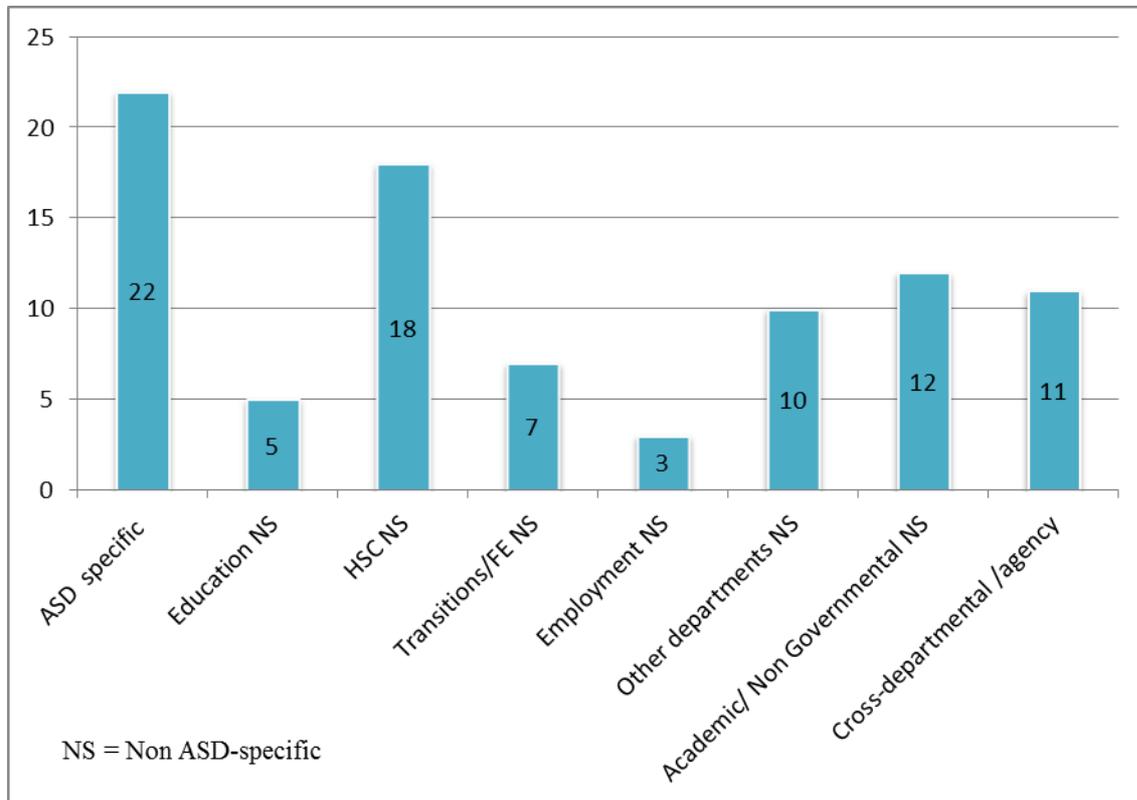


Figure 2 illustrates the breakdown of the NI reports and initiatives identified; although ASD-specific documents make up the largest category, the majority of relevant reports /action plans do not necessarily reference ASD to any great extent and some do not reference autism at all, even after the Autism Act (NI) was passed in 2011 (see Appendix 2). Of the total identified, eleven involved cross-departmental/agency working.

Reports and initiatives were reviewed regardless of their current status. Appendices 1 and 2 show a timeline of the currency of these reports/initiatives.

2.1 ASD-Specific Initiatives

2.1.1. Task Group Report on Autism. (Department of Education, 2002). (224 pages)

The Task Group Report on Autism (2002) was part of the North-South Ministerial Council initiative, that also included the Task Force Report on Autism (2001) published in the Republic of Ireland (see Section 2.5.7.1). The remit of the Task Group was ‘to make recommendations on educational provision for children and young people with autism’ (p.i). It was composed of a number of educational professionals (including two members of the Inspectorate, one from the Department of Education and one from the Department of Education and Science in the Republic of Ireland) and representatives from the voluntary sector. It did not include experts in the science that is considered to provide the best evidence base for treatment, ABA.

The Task Group made 43 recommendations, some of which were sub-divided further, e.g., Recommendation 3 (iii) outlined seven ‘principles to underpin planning of provision by Education and Library Boards’ (p.vii), and 7(i) which contained 11 recommendations for services for pupils of primary school age, to be provided by ‘ELBs, Trusts and voluntary organisations’ (p. xiii-xiv).

Taking these subdivisions into consideration, there were a total of 109 recommendations covering 11 themes:

- 1 Overview and structure of report,
- 2 Implication for educational provision (overview),
- 3 Implication for educational provision (approaches, perspectives and debates),
- 4 Prevalence and incidence,
- 5 Diagnostic services and early intervention,
- 6 Nursery and Pre-school provision,
- 7 Primary provision,
- 8 Post-Primary provision,
- 9 Provision for children with ASD and severe learning difficulties,
- 10 Provision for children with ASD and challenging behaviour, and
- 11 Further and Higher education, training and employment.

Many of these recommendations were aspirational rather than measurable and the report’s strengths lay in the more practical proposals, e.g., 5 (ii) – the involvement of Health Visitors in early screening, the development of a clear multi- agency pathway for diagnosis, with standardised training for the professionals (and parental involvement in the process), that were taken forward through a series of further reviews (see below). Other recommendations were only

partially successful, as with 5 (iii), where ‘a strategic programme of intervention... including home and centre-based provision’, more than 13 years later still relies on parents to seek out these interventions and rather than being provided by ELBs. All ELBs now have an ASD support team, and there is a degree of cooperative action with Trusts, as recommended.

In terms of interventions; however, the Task Group Report has been specifically criticised for its failure to adequately represent evidence-based interventions, such as those based on Applied Behaviour Analysis that are widely endorsed internationally (Perry et al., 2011; Reichow, Barton, Boyd, & Hume, 2014). The Task Group Report failed to assess interventions according to strength of evidence, and adequate training, home-school programmes, respite and summer schemes which were recommended are not always in place. However, other recommendations have been met, such as increased numbers of pre-school placements.

Individual Education Plans for primary school children now are standard practice, although ‘personal social education’ effected by Trusts and ELBs working together were not implemented comprehensively. Each ELB now has a transitions service with two Transition Co-ordinators for provision after a child’s 14th birthday. The Task Group Report also recommended the creation of a database to ‘identify numbers in Further and Higher Education, training and employment’ (11(vii), p. xxi) that has been implemented, at least in part.

The Code of Practice that was published along with the Task Group Report in 2002 still forms the basis of Department of Education policy for children and young people with ASD (Department of Education, 2014).

The recent review of Special Educational Needs (SEN) (*Every School a Good School - The Way Forward for Special Educational Needs and Inclusion*, 2013) underwent a consultation period from August 2009 to January 2010. The consultation responses have been published, and a policy memorandum paper agreed by the NI Executive was published in July 2012; a new Code of Practice is currently being drafted (see Section 2.4.5).

2.1.2. Independent Review of Autism Services 2007-2008 (Department of Health, Social Services and Public Safety, 2008). (108 pages)

The Independent Review of Autism Services (2007-2008) was a Department of Health, Social Services and Public Safety initiative. The then Minister, Michael McGimpsey, set up the

Independent Review of Autism Services in September 2007 with the aim of identifying gaps in service provision. The review team consisted of a panel of professionals associated with autism services in Health and Social Care and Education and again the panel did not include ABA experts, despite protestations from leading international academics and professional experts (Mattaini, 2008). The review was chaired by Lord Maginnis of Drumglass, who consulted with a range of professionals from government departments and agencies, specialists from Health and Social Care Trusts and educational establishments, politicians, and autism charities. He also invited contributions from parents/carers and families of individuals with autism.

In contrast to the Task Group Report, the Maginnis Review made only nine key recommendations (p.8). In no particular order of priority, they focused on increasing ASD service provision (including enhancing the role of Health Visitors in early screening, and producing consistent ‘care pathways’) and on autism awareness training for health and education professionals.

The lack of information and advice for parents was noted and it was recommended that this should be improved through integrating ‘treatment and advice centres’; yet, the exact content of treatment or advice was not specified. The Maginnis Review drew attention to the need for ‘consistent statistical information’ both on the number of individuals diagnosed with ASD and the services they were accessing, and the need for effective inter-departmental working, and raised the possibility of legislation to enable this.

The review team also proposed there should be a substantial financial commitment to ensure the delivery of these recommendations (p.66) and specifically identified budgetary needs of £1.75 million. They noted that ‘[i]n addition, there is a need for non-recurrent resources to address the acknowledged ‘backlog’ of cases requiring access to services’ (ibid.). Again the need for cross-departmental co-operation in terms of autism services was pointed out. As the Department of Health, Social Services and Public Safety (DHSSPS) was the lead organisation, recommendations for change in other areas (such as Education) were not addressed.

The DHSSPS took forward the Maginnis Review recommendations in 2009 with the publication of the Autism Spectrum Disorder Strategic Action Plan (covering 2008/2009 and 2009/2010). The Action Plan acknowledged that it was informed by two other important reports, the Bamford Autistic Spectrum Disorder recommendations and the Bamford Equal Lives Report (p.10).

Recommendations included a revised, coordinated referral system for all ages, with specific, reduced waiting times. Specialist local teams were set up and tasked to operate to a 'regionally agreed care pathway and standards' which included both diagnosis and follow-up support services and also incorporated performance indicators.

As a means of increasing early diagnosis and hence early intervention, it was recommended that training and support for parents should be provided, along with improved access to information on evidence-based assessment and interventions. The final recommendation was for increased 'partnership working', between government, families, community and voluntary agencies to raise awareness and provide more integrated services for individuals with ASD and their families. The ASD Strategic Action Plan aimed to improve services for individuals with autism and their families, through the formation of a Regional Autism Spectrum Disorder Network (RASDN).

2.1.3. Regional Autism Spectrum Disorder Network (RASDN).

RASDN was formed to implement the DHSSPS Autism Spectrum Disorder Action Plan (2008/2009 and 2009/2010). RASDN was a multi-agency/multidisciplinary framework that incorporated a Reference Group of parent/carers and individuals with ASD within each Health and Social Care Trust and also the overall Project Team, whose role it was 'to help shape the design of front line services' (Health and Social Care Board 2012a, p.2). RASDN was chaired by Dr Stephen Bergin from the Public Health Agency with the stated aim being to 'promote a 'whole life' approach, which recognised the importance of early intervention, provision of integrated health and social care services and linkage with education and other agencies as appropriate' (ibid., p.1).

The major outcome for individuals with autism and their families of RASDN was the re-organisation and integration of autism services within the Health and Social Care Trusts, each of which received a dedicated budget and a dedicated Autism Co-ordinator. RASDN developed a number of regional care pathway documents:

- *Six Steps of Autism care: for Children and Young people in Northern Ireland* (2011a),
- *Autism: A Guide for Families* (2011b) and
- *Autism: Adult Care Pathway* (2012).

The first two documents are available in an easy-to use folder format, and it was recommended that they should be given to parents/carers as part of the referral process. They are also available on the individual Trust and Health and Social Care Board (HSCB) websites. Adult services remain comparatively under-developed however (HSCB 2012b, p.8) and the adult care document, available only on the websites, did not provide extensive resources or rigor in promoting evidence-based interventions. Two other guidance documents were published: *Autistic Spectrum Disorder Transitions Guidance* (2011c) and *Autistic Spectrum Disorder Support: Along the Lifespan* (2011d, revised 2013).

All five Health and Social Care Trusts produced quarterly Trust Performance Reports for RASDN that were published in a regular summary document, thus detailing compliance of each Trust with the ASD Strategic Action Plan and listing initiatives, allocation of autism-specific posts and priorities for action. In addition, RASDN issued an annual Performance Report, which used a 'traffic light' target indicator system in respect of the five key themes (SPTCE):

- *Service redesign* to improve ASD care,
- *Performance improvement* of ASD services,
- *Training and raising awareness*,
- *Communication and information* for individuals and families and
- *Effective engagement and partnership* working (HSCB, 2012b, p.1).

2.1.4. The Queen's University Autism Research and Treatment (QUART) Forum

The Queen's University Autism Research and Treatment (QUART) Forum was established in 2010 to bring together a number of international research centres with academics working in the field of ASD. The QUART Forum is based on a philosophy of inclusion, evidence-based effective education, and rights-based person-centered research and practice with the mission to provide knowledge, values, and skills that improve parental and professional confidence and competence and lead to improvements for individuals on the spectrum, their families, and society. The QUART Forum includes members from across many academic disciplines from within QUB and national and international associates.

The research and education philosophy of QUART Forum is based on international peer-reviewed research evidence that shows that education and treatment that is based on the scientific discipline of behaviour analysis is the most effective way to help children and families affected by ASD to thrive. As a means to produce meaningful changes to behaviour applied behaviour analysis has demonstrated its effectiveness at the level of the individual, group and

community. This effectiveness has been highlighted by the large number of publications, spanning back five decades, illustrating significant behavioural change that can be maintained after the intervention has ceased across a range of settings and behaviours (including educational, health, animal welfare, sporting performance, and psychological well being)' (Mudford et al., 2009, p. 8).

The QUART Forum is hosted by the Centre for Behaviour Analysis, School of Education (QUB) and runs an annual multi-disciplinary research conference and bi-monthly workshops that are open to the public (www.qub.ac.uk/cba).

2.1.5. Autism Act (NI) (2011) and autism laws in other regions.

The governmental All Party Group on Autism (APGA; Report 99/08: Gribben 2008) promoted the Autism Act (NI) that was enacted in November 2011. The Act consists of three parts

1. The amendment to Schedule 1 of the Disability Discrimination Act that adds the following to the list of eight (a-h) defined areas of impairment covered under Schedule 1 of the Disability Discrimination Act 1995 (c.50)
 - (i) taking part in normal social interaction; or
 - (j) forming social relationships
2. The requirement to develop an interdepartmental Autism Strategy, giving overall responsibility to the Department of Health, Social Services and Public Safety (DHSSPS) to draft this strategy within two years of the Act being passed.
3. Supplementary, including the requirements that Health and Social Care Trusts return autism prevalence data to allow regular review and updating of the strategy (the Act states this must occur at intervals which do not exceed four years).

Under the Autism Act (NI) 2011, all government departments have an obligation to comply with the Autism Strategy (2013-2020) that identified their joint responsibilities (Article 2(8)) and produce a report of the implementation across all departments (Article 2(9)).

Under the auspices of the Autism Act (NI) individuals with autism were defined as those who have 'autism, Asperger syndrome, Rett's syndrome, Heller's syndrome or any pervasive developmental disorder not otherwise specified', and for the purposes of the Act, "carers" were defined as 'an individual who provides a substantial amount of care on a regular basis for that person' (see Supplementary to the Act).

Autism Legislation in other regions

In England and Wales, an Autism Act was introduced in 2009, ‘to make provision about meeting the needs of adults with autistic spectrum conditions; and for connected purposes’ (Autism Act, 2009, p.1). The devolved Governments in Wales and Scotland have developed their own initiatives (although not separate legislation) (see Section 2.5).

In the United States, the Combating Autism Act of 2006 (renewed in 2011) had a much more comprehensive remit than the Autism Act (NI) 2011 or the Autism Act 2009. The US legislation required the Secretary of Health and Human Services to:

- establish regional centres of excellence, operated through the Centers for Disease Control and Prevention (CDC);
- provide evidence-based interventions for individuals with ASD and their families;
- research and develop guidelines for evidence-based interventions, and to disseminate this information; and
- establish a continuing education curriculum for staff.

In the USA, health services are responsible for autism interventions that are viewed as medically necessary, e.g., ABA-based interventions (Freeman, 2003; Office of Personnel Management, 2013), and 38 States have enacted laws to mandate health insurance (including Medicaid) to cover these interventions (Autism Speaks, 2014; Diament, 2014).

2.2. Northern Ireland ASD specific reports

This section summarises reports either commissioned by government, or carried out by publicly funded research bodies.

2.2.1. Bamford Review of Mental Health and Learning Disability (Northern Ireland) Autistic Spectrum Disorders. (DHSSPS, 2006) (7 pages)

The Bamford Review of Mental Health and Learning Disability (Northern Ireland) included a specific report regarding Autistic Spectrum Disorders that focussed on three separate service

areas: mental health, learning disability and child health. The report made broad recommendations, in view of the fact that service development was uneven across the five local Health and Social Care Trusts. Six key areas were identified:

- Assessment and Diagnosis,
- Intervention,
- Individual and Family Support,
- Training,
- Management and Co-ordination of ASD Services, and
- Responsibility for ASD Services

The Bamford Review ASD Report included a series of recommendations for each action, including the need for setting up diagnostic centres within each Trust, specialised training for diagnosticians to ensure consistency, and the development of clear pathways for assessment.

Interventions following diagnosis were to be person-centred, based on the best available evidence and delivered by appropriately trained professionals, and if necessary on an inter-agency basis. Support needs were to include emotional support as well as practical aspects such as adequate respite and transition services and access to mainstream sport and leisure activities. Inclusion was to involve social skills development for children, and for adults, access to social groups that were to be tailored to their needs and interests. Adults with autism were to participate in developing these services. Employment and housing opportunities for adults with autism were to be made a priority.

In terms of staff training, it was recommended that awareness and specialist training should be offered regionally. While there was no specific requirement that training be University-based, the recommendation was that trainers should be accredited.

To facilitate management and co-ordination of services, the Bamford Report recommended that a key figure should be appointed in each Trust who would be responsible for development of ASD specific services, and that other agencies and voluntary groups should be included in service provision. Overall, the review did not recommend the development of a specific and separate programme of care, as it was thought that this could result in the diversion of resources and ‘could lead to further marginalisation of people with ASD’ (p.6).

The recommendations from the Bamford Review have been made repeatedly in other reports and initiatives regarding ASD, e.g., RASDN (Section 2.1.3), although many have not been fully implemented yet.

2.2.2. Meeting the needs of families living with children diagnosed with autism spectrum disorder (Keenan, et al., 2007) (184 pages).

The report *Meeting the needs of families living with children diagnosed with autism spectrum disorder* was funded by the Royal Irish Academy. It was the first major study of parent views and needs in a cross-border study, i.e., Northern Ireland (NI) and the Republic of Ireland (ROI). Quantitative and qualitative data were collected from 95 parents (caring for 100 children with an Autism Spectrum Disorder) and 67 multi-disciplinary professionals. Nearly half (45%) of the main parent/carer respondents from NI were unemployed, while 12% of their partners were unemployed; 7% were employed part-time. Of the children, 56% had a co-occurring learning disability, many of them categorized as ‘severe’ (Dillenburger et al., 2012).

This report, published five years after the Task Group reports in NI (2002) and ROI (2001) set out an agenda for change in service delivery, drew attention to the continuing lack of statutory service provision, delays in diagnosis and in obtaining a statement of special educational needs (Keenan, Dillenburger, Doherty, et al., 2010), and noted ‘deficiencies in the actualisation of parent-professional partnerships’ (p9). It established that the situation regarding evidence-based practice had not improved since the Task Group Report and that among professionals there was considerable misunderstanding around Applied Behavior Analysis (ABA) as the basis for interventions. The discrepancy between ABA-based provisions in NI and international best practice were identified (Dillenburger et al., 2010).

The report also noted the uncertainty around prevalence of ASD both in NI and in ROI, and the absence of a database that ‘offers one centrally governed dataset representative of all individuals with ASD residing in Local Trusts and/or who are under the jurisdiction of Education and Library Boards’ (p22).

A total of 35 recommendations were made around the central themes of

1. standardised testing and waiting times for diagnosis;
2. the increased implementation of evidenced-based intervention programmes both for early intervention and for continuous support in education; and

3. for a meaningful parent-professional partnership which actively engaged and gave value to parental experience.

‘In sum, there needs to be a co-ordinated holistic child- and family-centred systemic approach that is underpinned by science and data-based decision making and that is monitored comprehensively’ (p.129-130).

2.2.3. A Review of the Needs and Services for 10-18 year-old Children and Young People diagnosed with Asperger Syndrome living in Northern Ireland. A report for the Northern Ireland Commissioner for Children and Young People (NICCY). (Jones et al., 2007) (289 pages).

This review explored the needs of individuals with Asperger Syndrome by reviewing relevant current literature, services, policies and legislation and identifying examples of best practice both in NI and in the rest of the United Kingdom. Using primarily qualitative methods (interviews, questionnaires and focus groups, with individuals with Asperger Syndrome, their families and service providers) a limited analysis of data held by the Department of Education on pupils with Asperger Syndrome was also included.

The literature review was wide ranging and covered information on diagnosis, co-occurring conditions (including mental health issues), challenging behaviours and behaviour management, without referring to recent behaviour analytic literature. The 20 recommendations included

1. The establishment of a central database (on Asperger Syndrome) to which health, education and social care professionals contributed and to which they had access.
2. Effective management of the increasing caseloads of ASD support teams.
3. An audit of training (both in Education and Health and Social Care), reduced waiting times for diagnosis, less regional variation and better information and follow-up services for families.
4. An evaluation of the accessibility of services.
5. Guidance in selecting the most effective interventions at home and in school.
6. An increase the number of schemes available for out-of-school activities and breaks.
7. Increased transition, third level education and employment support.

Again, attention was drawn to the need for collaborative working between agencies (particularly in Recommendations 8, 9, 12 and 13), provision of services which were tailored to the individual (needs-led) rather than what happened to be available (resource-led) (Recommendation 15) and a

more positive and effective approach to post-secondary education options for young people with Asperger Syndrome (Recommendation 16).

2.2.4. Report 99/08: Improving Services for People with ASD. Research and Library Service for the Northern Ireland Assembly (Gribben, 2008) (32 pages).

This report was commissioned by the All Party Assembly Group on Autism and drew out possible government responses to the needs of individuals with an Autistic Spectrum Disorder.

It was composed of three sections:

- Section 1 described the needs of children and adults with autism,
- Section 2 set out current provision. The lack of available services was highlighted (Key Points 6 and 8), as was the absence of reliable data on prevalence (Key Point 7),
- Section 3 put forward three possible options for government action, with both the positive and potentially negative aspects of each course of action.
 1. Option 1: Continuation of existing policy mechanisms to provide services but apply additional funding and earmark resources to the task (the current strategy in England and Wales).
 2. Option 2: Developing a specific cross cutting strategy (as with the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, however, much less radical than the Welsh strategy).
 3. Option 3: Creating a legal obligation for action on ASD by enshrining it in legislation.

2.2.5. Autism: A guide for criminal justice professionals. A report by the National Autistic Society in collaboration with the Department of Justice (2014) (32 pages).

This guide related to the Autism Strategy (Northern Ireland Executive , 2014a; see 2.7.2), where Theme 9 and Strategic Priority 13 referenced the need for ‘protection, support and information’ for individuals with autism who have contact with the justice system, as well as improved guidelines for practitioners (ibid. p 11, 74-75). The report covered five key areas within separate sections, illustrated by case studies;

- Section 1 described the key features of autism and how to recognise them.
- Section 2 discussed the importance of this knowledge in relation to interpreting and managing the behaviour of people with autism, particularly when they were confronted

with stressful or unexpected changes which may lead to (often unintentional) unlawful activity.

- Section 3 looked at examples of how characteristics associated with autism (such as naivety, inability to pick up on social cues, or obsessional behaviour) had brought individuals into contact with the justice system. It also emphasised that only a minority of people with autism were likely to be thus involved, either as offenders or victims.
- Section 4 outlined practical advice for professionals, with the aim of ensuring that they had an ‘informed approach’ when dealing with individuals whose behaviour suggested they may be on the autism spectrum, giving relevant examples. This section also included suggestions for effective communication strategies (and drew attention to the autism recognition cards carried by individuals, issued by a number of charities).
- Section 5 offered guidelines for questioning, and discussed the role of a registered intermediary, psychologist or social worker with specialist training in autism.

The guide also emphasised that the approach should be very similar to that followed with any person who might be regarded as vulnerable and who was in a potentially stressful situation. The guide included an Appendix containing contact details and specialist resources (including the Advocate’s Gateway toolkit for ASD and an e-learning course run by the Royal College of Speech and Language Therapists).

Neither the Community Safety Strategy (Department of Justice, 2012) nor the Review of the Youth Justice System in NI (Department of Justice, 2011) referred to ASD, although the latter noted the disproportionate numbers of ‘special groups’ which include young people with ‘mental health problems’ (pp.13, 86-89), ‘speech, language or other communication difficulties’ (p.67) and learning disabilities/difficulties (ibid. p87, 89).

2.3. ASD Charity reports

This section considers reports commissioned and/or funded by some of the many autism charities in NI. Project evaluations are not included.

2.3.1 ‘I Exist’: The message from adults with autism in Northern Ireland. A report for the National Autistic Society. (Stewart, S., 2008) (38 pages).

This report was based on a survey of experiences of adults with autism in NI and formed part of the *I Exist* campaign to raise awareness of autism in light of the Maginnis Review of Autism

Services (see 2.1.2.). The report documented the lack of awareness around autism among the general public, the social needs of adults with autism and the impact on families. It also noted the very limited services offered for adults with ASD, the difficulties of obtaining a diagnosis, and the fact that Trusts did not have accurate data on the prevalence or service usage data on adults with ASD in their area.

The report highlighted the need to ‘bridge the gap’ between Mental Health and Learning Disability services, and called for person-centred planning. Findings showed that the uptake of Direct Payments among respondents was very low (20%), likely due to lack of available information or funding constraints. The report concluded that the needs of many adults with ASD in NI were not being met and that there should be greater involvement of adults with ASD in decision-making.

2.3.2 Is anyone listening? A report on stress, trauma and resilience and the supports needed by parents of children and individuals with ASD and professionals in the field of Autism in NI. A report for Autism NI. (Burrows, R., 2010) (96 pages).

This report was commissioned by the charity AutismNI to explore the effects of stress on individuals with autism, their families and the professionals involved in ASD service provision. The report focused on the social, emotional and financial consequences of living with a family member with ASD and the emotional consequences for service providers. Although no definition of anxiety was given, 90% of the 141 parent respondents reported that they experienced ‘significant anxiety’ and 57% reported ‘acute anxiety and panic states’. In addition, over 50% of mothers reported that they were ‘taking medication’, although the type and/or frequency of medication was not outlined (ibid.).

Much of this report focused on a deficit model of grief, loss, and ‘survival’ of ASD diagnosis. The report also drew attention to the stress incurred by professionals. Recommendations included the need for

- Prevention of stress and crisis, by proactive service provision;
- Protection through anti-discriminatory measures that take into account autism as a ‘disability’; and
- Provision for safety, development and well-being.

2.3.3 Employing People with Autism: A Brief Guide for Employers. (National Autistic Society, 2011) (20 pages).

Focussing on employment, this short document was produced by the National Autistic Society (NAS), working with the Department for Employment and Learning, the Equality Commission for NI, and Employers for Disability NI. It drew attention to the fact that there were an estimated 17,000 individuals with autism in NI and that only 15% of adults with autism were in employment, although many more were capable and wanted to work.

Written in very practical terms, this guide offered a brief overview of ASD and outlined the advantages of employing an individual with autism, the practical adjustment that may be needed to recruit and maintain someone with autism in the workplace, and the support from government departments and agencies that were available for employers and their employees. It also informed employers about the Disability Discrimination Act 1995 (DDA) and the duties this imposes; this part of the guide pre-dates the Autism Act, that supplemented the DDA. The guide was illustrated with short case studies and the final section contained contact details for employers.

2.3.4 A* is for Autism: Make every school a good school. A report for the National Autistic Society. (Stewart, S., 2012) (36 pages).

This report focussed on education and was published while the SEN review was in progress. Findings were reported from a survey of 151 parents and carers of school-age children and 66 children and young people with autism. Four areas of concern were highlighted:

1. The need for timely and appropriate educational responses (52% of parents reported they had waited over one year and a further 22% had waited two years or more).
2. Autism training in schools for all levels of staff (42% of young people felt their schools did not know enough about autism). This training should be reflected in practice, for example in teaching styles, in regard to bullying and in transition planning.
3. Parents felt there was a lack of choice in schools, with just over half saying they would prefer autism specific schooling.
4. Conflict or complaint, with 45% of parents reporting that they would not be confident about school decisions.

The report looked in some detail at the proposed reforms of the SEN review, highlighting concerns about the Co-ordinated Support Plans (CSP) and the effects of the new assessment

process, which, respondents feared, would exclude some children with current Statements of Special Educational Needs. Participants were generally supportive of the proposed Personal Learning Plans (PLPs) but indicated that these should be outcome-focused. Recommendations (p. 30-32) included:

1. Need for clear pathways for support in the Code of Practice, with inter-agency support.
2. No loss of statutory provision for children moving from Statementing to a CSP.
3. The need for measurable outcomes in each PLP.
4. A transparent mechanism for complaints.

2.4 Relevant non ASD-specific reports and initiatives

The reports by Government Departments, Agencies, academic institutions and Commissioning Bodies that were relevant to ASD were included under six categories: Health and Social Care, Education, Housing/Independent Living, Transitions, Employment/Inclusion/ Poverty, and Cross-Departmental reports.

Health and Social Care

2.4.1. Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland. Bamford Review. (DHSSPS, 2005) (182 pages).

This report formed one strand of the overall Bamford review of policy provision, legislation and services for people with mental health problems or learning disabilities that was set up in 2002 by the DHSSPS. While it was not autism specific, it was relevant for individuals with autism who also have learning disabilities. The working group that produced the report held a series of consultations with individuals with learning disabilities and their carers and set up the Equal Lives Group of individuals with learning disabilities who provided input to the review. They also established six Task groups to focus on the areas considered of particular significance:

1. Support for Children and Young People and Their Families,
2. Accommodation and Support,
3. Day Opportunities,
4. Ageing,
5. Mental Health and
6. Physical Health.

The report identified 12 key objectives for improving the lives of people with learning disabilities through future policy development. In analysing existing services over the past 20 years, improvements were noted particularly in the reduction of placements in residential hospitals, the development of paediatric services, and an increase in the number (and quality) of placements for day care and for childcare.

However, the absence of accurate data on service uptake and in particular, lack of research into the cost-effectiveness of services was highlighted. In all, 74 specific recommendations were listed, based on the 12 key objectives and covering the issues identified for children, young people and families, inclusion and ‘fuller lives’, accommodation and support, health, mental health and challenging behaviours, and ageing. The report emphasised the fact that learning disability resulted in inequalities for both children and adults.

2.4.2. Implementing Bamford: Knowledge from research. (DHSSPS, 2011) (16 pages).

This was a short report representing a summary of rapid research reviews around the priority areas from the Bamford recommendations. It was based on a consultation process facilitated by HSC Research and Development Service between users of research (policy makers, commissioners) and service users, patients, clients and carers.

The brief review of ‘Supporting people with Intellectual Disabilities who Challenge or who are Ageing in Northern Ireland’ (Slevin et al. 2011a; b) was that was based on literature from 2001-2011 and looked at practice and policy implications for a very specific population (those with ‘intellectual disabilities’) in view of their increased longevity. While not autism-specific, this report was relevant for older individuals with ASD who have a co-occurring learning disability and/or challenging behaviour.

Among the report’s recommendations were the development of specialist mental health teams, early succession planning, and improved day-care /respite settings for older individuals with learning disabilities, including those of statutory retirement age. In terms of policy, the review indicated that there should be more community-based services and better collaborative working between mainstream and learning disability services, particularly in mental health/dementia provision.

The review identified ‘gaps’ in current practice and policy, such as a need for a comparative analysis of the effectiveness of challenging behaviour teams across the five local HSC Trusts. The review recommended that Trusts should identify ‘innovative’ models of day-care for individuals with challenging behaviour.

Some of these recommendations applied equally to individuals with autism who do not have either a learning disability or challenging behaviours, such as education and support provision for parents and carers in regard to ageing, and health screening for physical and mental health problems.

2.4.3. Transforming Your Care: A Review of Health and Social Care in Northern Ireland. (DHSSPS, 2011) (213 pages).

This was a review of the provision and accessibility of services across all aspects of HSC services, with the aim of identifying good practice and good models of service delivery. The review did not make specific reference to individuals with autism, but since they require access to ‘core services’ they would benefit from the proposed changes to service delivery, including increased patient-centred care, preventative strategies, evidence-based practice and innovative approaches. Of particular relevance to adults with autism were the recommendations of the promotion of ‘independence and personalisation of services’ (p.95) and the development of ‘a more diverse range of age-appropriate day support and respite and short-break services’ (p. 139).

The proposals shifted focus from primarily day centre-based activities to meaningful, diverse community centred day opportunities that do not offer a ‘one-size fits all service’ (ibid., p. 95). It was recommended that there should be more peer and independent advocacy and carer support (ibid.). The post-consultation report noted that increased availability of ‘self directed support’ packages and individual budgets would allow adults with autism to explore more ‘creative, age-appropriate opportunities to promote independence and choice, such as access to employment, leisure and educational activities’ (DHSSPS 2013, p. 83). The proposal required more partnership working with other statutory bodies, with carers and service users and the voluntary sector.

Education

2.4.4. Every School a Good School: A Policy for School Improvement. (Department of Education, 2009a) (76 pages).

The focus of this policy document was to improve educational achievement and accountability for attainment of standards in primary and post-primary schools. It set out 12 key principles including ‘equity of access and provision’ and recognition of the diversity of need.

Although this document did not specifically mention children with ASD, it acknowledged that ‘the provision of good support for those pupils with special educational needs in mainstream schools is improving but in the majority of schools inspected it is not good enough’ (p.11).

The report also noted that ‘reassuringly, the overall performance in special schools was seen as good’ and cites the Chief Inspector report, ‘almost three-quarters of the schools inspected were good or better and are effective in meeting the academic and social needs of almost all of their pupils’ (p.11). Taking into consideration the poor performance of mainstream schools, the report indicated that the education system still failed a significant number of children with disabilities.

2.4.5. The Review of Special Educational Needs (SEN) and Inclusion: Policy Development. (Minister’s Presentation to the Committee for Education, 2012) (51 pages) subsequently published on the Department of Education websites as a **Summary of Key Policy Proposals July 2012.** (56 pages)

This review had the potential to have major implications for school-aged children with special educational needs, by including a new category of Additional Educational Needs (AEN) and proposing to replace Statements of Special Education Needs (SEN) with the new concept of Co-ordinated Support Plans (CSP). However, following extensive consultations with stakeholders, the proposal was significantly revised to allow for the maintenance of Statements of SEN, if required. The Minister for DHSSPS stated that ‘the existing legislative definition of SEN will not change...[t]he framework will work within the definition of disability, as defined by the Disability Discrimination Act 1995 and applicable to SENDO 2005’ (p.5).

In terms of pre-school provision, the paper set out that appropriate SEN provision must be available and there would be a revised ‘SEN statutory code of practice on pre-school provision and associated ELB/ESA supports’ (p.15). The original proposal for Early Intervention Officers was revised to include Pilot Early Intervention Teams that were to have an assessment and multi-disciplinary support function. The revised proposal still included transition arrangements for pupils entering post-primary schools. Within the new framework, children from the age of 14 were to have access to Education Transitions Co-ordinators (ETC). The new framework also was to include increased support from HSC Trusts, with appropriate provision included in the ‘Statement of needs’ within the CSP, where necessary. Multi-disciplinary Groups (MGs) were to be piloted across all five ELBs to target early identification and intervention in pre-school settings.

Arrangements for partnership working (with parents and professionals and across sectors) were to be explicitly set out in a new Code of Practice. The Education and Training Inspectorate were to be commissioned to review existing partnership working within schools. Parents were to have the right to appeal decisions about the identified needs and specialised provision (i.e. a Statement of SEN) detailed in a CSP.

The finalised proposals were published in July 2012 and required draft legislation, supporting regulations, and a statutory code of practice to support the new SEN framework (Minister for Education, cited by SENAC, 2013). It was anticipated that the new framework would be in place by the school year 2014/2015, although there would be a 5 year ‘transitional period’ (ibid.). However, to date, the required legislative structure is not in place (December 2014).

Housing/Independent Living

2.4.6. Supporting People, Changing Lives: The Supporting People Strategy 2005-2010.

(Northern Ireland Housing Executive. (NIHE, 2005) (90 pages).

The Supporting People (SP) programme operated throughout the United Kingdom and was introduced as a means of reforming housing support services. It was implemented in NI in 2003 and administered by the NI Housing Executive (NIHE, 2005), within the Department of Social Development (DSD). Individuals with autism were included, but only as a sub-category of individuals with a learning disability (LD), i.e., an estimated 50% of individuals with ASD have co-occurring LD (National Audit Office 2009, p.5).

Services for individuals with learning disabilities accounted for 22% of the budget (compared to 24% in England), with shared supported housing as the principal housing category (NIHE p.32).

After public consultation, NIHE was due to release a new housing support strategy for 2011-2015, but the Department of Social Development postponed this while waiting for the outcome of a review of the SP Commissioning Body (NIHE, 2013).

Transitions

2.4.7. Report of the Transitions Inter-Departmental Working Group. (Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety, 2006) (58 pages).

In 2002 the Department of Education (DENI), DHSSPS, and the Department for Employment and Learning (DEL) formed an Inter-Departmental Group (IDG) to consult with parents, professionals and voluntary groups about the needs with regard to transitions process for young people with Statements of Special Educational Needs. In educational terms, 'transition' referred to the period of planning for leaving post-primary schooling. The issues under consideration included the inflexibility of day care services for young adults, the lack of coordinated advice, and the limited opportunities for young people to access vocational or Further Education (FE) courses and suitable and/or supported employment. In addition, the report identified that while at school, young people did not receive adequate preparation for adult life, inadequate training in life skills, and little opportunity for work experience.

In response, the IDG produced an Action Plan, which carried practical proposals and the assurance of a dedicated budget. The report emphasised the need for 'Government Departments and agencies to act collaboratively' (p.9). This was considered particularly important given that the options available to school leavers encompassed education, employment, and health and social care placements. The 20 key actions proposed in this report included the call for funding to

1. provide age-appropriate placements in adult day care centres,
2. to fund Health Trusts and Boards to employ Transitions Officers, and
3. to enhance a range of further education and training provision by providing a suite of 'prevocational' education and training programmes for young people'.

The Inspectorate had highlighted the shortage of placements for pupils leaving Schools for Learning Difficulties/Disabilities (SLDD) and the report noted that ‘100 extra day care places have already been created’ (p.ii). Funding was allocated to the Education and Library Boards to provide life skills training for independent living. Careers guidance in schools was to focus on children aged 14 and over with SENs and, within the FE sector, DEL was to provide extra funding to encourage widening access.

In a pilot scheme, transitions co-ordinators were employed in each ELB. The evaluation in nine special schools (Education and Training Inspectorate, 2008) indicated that the role of the Transition Co-ordinator was ‘developing well and has established a positive working ethic and approach, which is supporting the well-established transitions provision in the special schools, [although they should] identify benchmarks of good practice, and ensure stronger collaborative working across the health and education sectors’ (p.10). However, concerns persisted about the transitions processes and day-care remained under pressure, with school leavers greatly outnumbering available places as well as opportunities in employment and education (Dillenburger & McKerr, 2009; 2011; Lundy, Byrne, & McKeown, 2012, see below).

2.4.8. A Review of Transitions to Adult Services for Young People with Learning Disabilities in Northern Ireland. A report on behalf of the Northern Ireland Commissioner for Children and Young People. (Lundy, et al., 2012) (82 pages).

The Commissioner for Children and Young People introduced this report by making the point that some of the most common issues referred to her office related to the transition of young people with learning disabilities from children to adult services. She expressed concern about ‘the enduring nature of barriers to the full realisation of children’s rights in this area’ (p.1-2). This report explored transition issues in relation to education, employment, training and health and social care.

Key findings of this report indicated that although Supported Employment had grown, access to schemes was regionally variable and remuneration and allocation of labour was not commensurate with ‘mainstream’ employment. The report pointed out that there were no specific statutory obligations to support transitions of young people with learning disabilities.

In terms of health and social care, the report identified a need for more choice, flexibility, and person-centred provision and information. Concerns about staffing levels and resources were

also expressed especially with regards to people with profound disabilities, and those with behaviour that challenges.

Thus, six years after the IDG Working Group (2006) had published their recommendations, the issues around lack of support, work experience and day provision were still causing concerns.

Employment/Inclusion/ Poverty

2.4.9. Child and Family Poverty in Northern Ireland. A report for the OFMDFM.

(McLaughlin, E. & Monteith, M. 2006) (144 pages).

This research report was produced under the Equality and Social Inclusion in Ireland project, by University College Dublin and Queen's University Belfast. It built on the earlier Poverty and Social Exclusion Study Northern Ireland (2003) and referenced *The Bottom Line* Report (2004). The particular focus of this report was child poverty and the way in which information and implications for other policies and strategies was captured.

Findings showed that circumstances that correlated with child poverty included lone-parent families, families with no-one in employment, those who live in social housing, and those with a family member (adult or child) with a disability. The lack of necessities across five domains, i.e., food, clothing, participation and activities, developmental, and environmental, indicated that 'a considerable proportion' of children in NI lack more than eight of the 'basic necessities of life'.

Since these findings related to all children, they did not adequately represent the additional economic or quality of life stresses incurred by families with a child with disabilities, e.g., loss of gainful employment of the main caregiver, the need for assistive technologies, special clothing and/or diet requirements, as well as additional cost for accessing transport and activities. The authors also indicated that lack of good quality childcare in NI was one of the limitations of 'the welfare-to-work strategy' (p. 123). The report concluded that, in order to eradicate child poverty and promote equality of opportunity, government would have to commit to a new strategy and increased financial investment.

2.4.10. Report of the Promoting Social Inclusion Working Group on Disability. (OFMDFM, 2009) (161 pages).

The Promoting Social Inclusion (PSI) Working Group on Disability was established by the OFMDFM to identify and address barriers for individuals with disabilities. It included representatives from disability groups (although none from the autism sector), NI Commissioners for Equality, Children and Young People, and Human Rights, and representatives from ten government departments.

The very wide-ranging findings of this report were presented in a series of themes, including equality, choice, early years, transitions, independent living (including life-long learning), employment, and information/communication, as well as ‘bringing about change’. There were three autism specific references: the Ten-Year plan (p. 22), a short case study of the Wraparound pilot project, seen as a possible model for future support for other children with disabilities (p.50) and the use of supportive technology (p.72).

This report took a life-span perspective, acknowledging that different needs arose over time, although it did not specifically address the needs of older (i.e. post-retirement age) individuals with intellectual disabilities (ID). The report made a total of 83 detailed recommendations, including specific recommendations for lead government departments; it also referenced the forthcoming ‘Strategy to improve the lives of disabled people’ (ODFDFM 2013).

The report concluded that strategic action by government was not enough to overcome barriers as ‘there are deeper attitudinal and cultural changes that need to take place before disabled people can truly experience better life chances and participate on an equal basis as citizens’ (p. 151).

2.4.11. Priorities for Youth: Improving Young People’s Lives through Youth Work.
Consultation document. (Department of Education, 2012) (34 pages).

This consultation report highlighted the need for an integrated approach to youth work within the Education system, as a means of engaging and offering skills to young people. It was proposed that the Youth programme would be delivered under the new Education and Skills Authority (ESA) framework, with targeted funding to ‘help meet the needs of specific groups of young people, within the Section 75 grouping... [including] young people with a SEN or with

disabilities’ (p.23). Consultations closed in December 2012 and the consultation findings were published in October 2013 (Department of Education, 2013).

2.4.12. Welfare Reform Bill: Regulatory Impact Assessment. (Department of Social Development, 2012) (77 pages).

In 2012, the Welfare Reform Act came into force in England. It initiated major changes to the benefits system, including the introduction of Universal Credit and also the new Personal Independence Payment (PIP) that was to replace Disability Living Allowance (DLA). The latter was of particular importance for individuals with ASD, as all those currently receiving DLA would be re-assessed under new criteria. DLA was also a ‘passport’ benefit and the Department of Work and Pensions indicated the somewhat complex mechanism by which those receiving benefits as a result of entitlement to DLA could access similar benefits, if in receipt of PIP (DWP, 2012, p.33-36). PIP assessment criteria did include ASD as a developmental disorder (DWP 2013, p.53) but did not specify the many ways in which individuals may be affected.

In the devolved administration for NI, these benefits would be administered by the Department of Social Development, in a Welfare Reform Bill. The regulatory impact assessment stated that the NI policy proposals would ‘largely mirror those contained the UK Westminster Bill’ (p.6). It stated that PIP was designed to ‘support disabled people who face the greatest barriers to leading full and independent lives’ (p.6-7). The training of assessors would need to ensure that they were aware of the subtle disabilities that impact profoundly on the ability of individuals with ASD to enter into the employment market. A public consultation on DLA reform closed in February 2011 (throughout the UK) and the legislation in England came into effect in April 2013. At the time of the completion of the present study (Dec. 2014), the Bill was at the Committee stage in NI (Northern Ireland Assembly 2013).

2.4.13. Disability programmes and policies: How does Northern Ireland measure up? Monitoring Implementation (public policy and programmes) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Northern Ireland. A report prepared by Disability Action for the Equality Commission for Northern Ireland. (Harper, McClenahan, Byrne, & Russell, 2012) (343 pages).

The UK signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and therefore is bound by and monitored for its implementation. Using questionnaires, active involvement of individuals with disabilities, e.g., in focus groups, and a thorough analysis of policies, programmes and guidelines in NI, this report aimed to identify good practice as well as areas of substantive shortfalls in the implementation of UNCRPD in NI.

While not referencing autism specifically, the report identified a number of important issues, including inaccessibility of relevant reports, scarcity of ‘disaggregated’ data, a lack of a central system for accessing disability information, and reluctance to participate in the study by some government departments (p.36), that were ‘intractable or persistent and/or one on which little progress is being made [and that were] disproportionately damageing, i.e. the group affected may be small but the impact substantial [concluding that] the ‘direction of travel’ is negative i.e. existing evidence shows a worsening experience for disabled people’ (p. 40).

The report concluded that the UNCRPD was not being fully implemented NI in three areas (p.271):

1. Awareness raising (Article 8),
2. Participation in political and public life (Article 29), and
3. Statistics, data collection and access to information’ (Articles 9, 21 and 31).

In addition, the report highlighted the ‘cross-cutting’ implications of deficits, affecting other areas of life and policy making and the need for increased participation of individuals with disabilities and their families.

Cross-departmental reports

2.4.14. Our Children and Young People – Our Pledge. A Ten-Year Strategy for Children and Young People in Northern Ireland. (OFMDFM, 2006) (98 pages).

This document set out how, by targeting services for the most disadvantaged (including people on the autism spectrum), the government could improve outcomes for all children and young people over a ten-year period from 2006 to 2016. Linked to a detailed series of key indicators and identifying the lead government departments responsible for delivery, six outcomes were targeted so that children

1. were healthy,
2. enjoyed learning and achieving,
3. lived in safety and with stability,
4. experienced economic and environmental well-being,
5. contributed to community and society, and
6. lived in a society which respects their rights.

To deliver and monitor this strategy, a Planning and Review Panel, a Practitioner’s Group, a Parent Advisory Group and a Research and Information Group were set up.

The main data source was the DSD Family Resources Survey. The key outcome measures and mechanism for delivering change included the percentage of children living in absolute low-income poverty, the ‘new deal for lone parents’, the Fuel Poverty strategy, and the Supporting People housing strategy. Educational indicators were attainment-based (e.g., achievement at Key Stages, GCSE and moving into Further or Higher Education), and did not include specific measures for children whose school performance was affected by disability, such as autism. Participation in sport and leisure was gauged by responses to the Young Person’s Behaviour and Attitude Survey that did not include special and independent post-primary schools (Northern Ireland Statistical Research Agency; NISRA 2010).

2.4.15. Northern Ireland Children & Young People's Plan 2011-2014. (Children and Young People’s Strategic Partnership [CYPSP] 2011) (205 pages).

Under the lead of the Health and Social Care Board (HSCB), the Children and Young People’s Strategic Partnership (CYPSP) brought together agencies responsible for children’s health and development. This report was designed to be a ‘live document’, in that web links existed

throughout that connected the reader to the current stage of the Action plan. As this was not an ASD-specific report, the focus was on general early intervention for children and young people in line with aims identified in *Our Children and Young People: Our Pledge* (DHSSPS, 2006, see 2.4.14). The CYPSP was designed to operate within a framework of Regional sub groups, outcomes groups, and locality groups delivering outcomes-based planning and playing a role in the implementation of the Autism Strategy (2013-2020) (Northern Ireland Executive 2014).

One of the aims of the initial 3-year Plan was to map the provision of early intervention services across NI and establish ‘how they currently connect to each other, with the aim of putting in place, in every area of NI, a joined up network of early intervention supports and services, which build on and link to universal services’ (p.8-9). An early intervention subgroup was set up with the aim of identifying the ‘key strategic drivers’ existing for services for early intervention. The report defined early intervention as

‘intervening early and as soon as possible to tackle problems emerging for children, young people and their families or with a population at risk of developing problems. Early intervention may occur at any point in a child’s life’ (p. 41).

As part of the commitment to cross-departmental working, a ‘Family Hub’ service was initiated through a website (www.familysupportni.gov.uk). The OFMDFM commissioned the United Nations Education, Scientific and Cultural Organisation (UNESCO) Chairs Programme to ‘refine a set of indicators that can support it reporting to the Committee on the Rights of the Child and also measure the effectiveness of the Ten Year Strategy’ (p. 34); CYPSP staff were members of the reference group.

2.4.16. Improving Children’s Life Chances. (Northern Ireland Executive, 2011) (59 pages).

The *Improving Children’s Life Chances* report set out the strategy aiming to achieve the target set by the Child Poverty Act (2010), i.e., to eradicate child poverty by 2020 through improving parental economic circumstances. All children were to have an ‘equal chance to flourish, to learn and grow and to access opportunity that will allow them individually to realise their full potential’ (p.3). Although there was no specific mention of ASD, children of parents with disability were considered to be at increased risk of poverty.

The first annual report was published by the Northern Ireland Executive in May 2012 (23 pages). Families of adult sons/daughters with a disability (cf. Dillenburg & McKerr, 2011) were

affected by Notes 17-21 that dealt very briefly with proposed changes to the welfare system (Welfare Reform Act 2012), in particular to Employment and Support Allowance. Note 45 mentioned integrated affordable accessible childcare as a pre-requisite for employment, but did not refer to the lack of adequate childcare for families with children with disabilities (Employers for Childcare 2011).

2.4.17. A Strategy to Improve the Lives of Disabled People. (OFMDFM, 2013) (54 pages).

Aiming ‘to give coherence and guidance to government departments’ activities across general and disability specific areas of policy’ (p.11) this strategy built on the PSI Working Group on Disability (2009) (2.4.10) and identified 18 strategic priorities grouped under the following themes:

1. Participation and active citizenship (Priorities 1-2),
2. Awareness raising (Priorities 3-4),
3. Accessibility (Priorities 5-7),
4. Independent living/Choice and control (priority 8),
5. Children, young people and families (Priorities 9-10),
6. Transition from childhood to adulthood (Priorities 11-14),
7. Employment and employability (Priorities 15-16),
8. Justice and community safety (Priority 17)
9. Being part of the community (Priority 18).

While most of these priorities were relevant to ASD, autism was referenced only once, in relation to the need for training for the Prison Service in dealing with vulnerable young people.

This strategy was taken forward through the *Delivering Social Change Framework* (see 2.6.1) and identified seven work streams:

1. Disability Awareness and Advocacy,
2. Access, particularly access to Transport, and Digital Inclusion,
3. Housing,
4. Employment and Standard of Living,
5. Tackling crime against people with disabilities,
6. Participation in sports and leisure, and
7. Monitoring and Reporting.

The 1st Annual Report (OFMDFM, 2012) acknowledged the continuing economic recession and focused on increasing employment for parents and educational opportunities for disadvantaged children.

2.4.18. What the future holds. Older people caring for adult sons and daughters with disabilities. Report produced for Changing Ageing Partnership (Dillenburger, K. & McKerr, L. 2009) (150 pages).

This report focussed on ageing and disability, in particular looking at how older caregivers (aged 60+ years of age) were affected in the latter part of life. Based on interviews with 29 parents who cared for 27 adult sons and daughters with disabilities (many diagnosed with ASD), present life circumstances, support from family and service providers, levels of health and impairment, and futures planning were assessed. Findings showed that carers experienced twice the level of psychological stress expected in the general population. Their lifestyle was not what typically of retired citizens, in fact, their life style was determined by worry, loneliness, and severe lack of statutory support. Over 70% had not made any plans for the future.

The report made five recommendations:

1. Evidence-based early interventions should be in place to enhance life skills and choices of individuals with disabilities.
2. An advocate should be available to each family throughout the life span, to help set up and coordinate appropriate networks of support well in advance.
3. Suitable alternative accommodation needs to be available for adults with all levels of additional individual needs.
4. Support services for adults with disabilities who live at home and their carers should be easily accessible, especially in rural areas.
5. Education and training for service providers needs to focus on evidence-based best practice to meet the needs of these families.

2.4.19 Caring for sons and daughters with disabilities across the life course: Hearing the Data. Report for OFMDFM (Dillenburger, K. & McKerr, L. 2011) (145 pages).

This report assessed childcare issues for sons and daughters with disabilities (many with ASD) across the whole lifespan; 38 service users, i.e., 29 parent/caregivers and 9 young adults with learning disabilities; as well as 13 service providers from the statutory and voluntary sector, e.g., child-minding association, social services, carers' organisations were interviewed.

Findings confirmed stress levels in caregivers that were twice that of the general population and indicated that parent/caregivers wanted to get the best available life for their son/daughters. With increasing age across the lifespan, parent/caregivers worried more and more about the future and generally felt that they knew more about their son/daughters' needs than service providers who did not to always listen carefully enough. Recommendations pointed out the importance of

1. Finding dependable peer support throughout the lifespan,
2. Encouraging and empowering parent/caregivers to self-determination,
3. Cost-effective, evidence-based early intensive behavioural intervention (EIBI),
4. Adequate transition services between Children's and Adults' services in HSC Trusts and within Education and Library Boards,
5. Integrated childcare strategy for children with disabilities/special needs.
6. Joined-up services across education, health, and social care (and Children's and Adults' services),
7. Access to clear information on benefits, direct payments, carers' assessments and work support schemes,
8. No financial penalty when carers retire from their jobs,
9. Registered day-care establishments (crèches, nurseries, playgroups etc.) to have the equivalent of the Special Educational Needs Co-ordinator (SENCO)
10. Schools to have staff with an established skills base, in-school provision
11. Colleges, workplaces and adult centres putting in place robust, individualised support systems.
12. Both policy makers and practitioners being knowledgeable about the most up-to-date, evidence-based, international best practice interventions.

2.4.20. Disability policies within education and employment organisations.

Under Section 75 of the Disability Discrimination Act (2006) designated bodies (i.e. public authorities) must have an Equality Scheme in place, which applied both to those who use their services and to their employees (Equality Commission 2012). In addition, a number of these organisations (currently 179) must submit an Annual Progress Report to the Equality Commission. While there are too many to review in this report, these schemes should be relevant to individuals with ASD, both as employees and as service users.

Section 75(3) (revised) defined a public authority as:

- any department, corporation or body listed in Schedule 2 to the Parliamentary Commissioner Act 1967 (departments, corporations and bodies subject to investigation) and designated for the purposes of this section by order made by the Secretary of State;
- any body (other than the Equality Commission) listed in Schedule 2 to the Commissioner for Complaints (Northern Ireland) Order 1996 (bodies subject to investigation);

- any department or other authority listed in Schedule 2 to the Ombudsman (Northern Ireland) Order 1996 (departments and other authorities subject to investigation);
- any other person designated for the purposes of this section by order made by the Secretary of State.’ (Equality Commission 2013).

2.5 Relevant reports from elsewhere in the UK and Ireland.

2.5.1. Strategic Action Plan for Wales. (Welsh Assembly Government 2008) (73 pages).

This Action Plan was launched in 2008, ahead of the Autism Act of 2009 which set out the legislative context for adult autism services in England and Wales. The Action Plan aimed to address ‘lifespan’ autism services in the areas of health, social care and education. The initial phase (‘Foundations’) focused on raising awareness and documenting existing autism services for effective future development (for children and for adults), including effective transition arrangements. Care pathways were included as appendices. The Action Plan was evaluated after 2 years (Welsh Assembly Government, 2011). The evaluation found ‘significant and demonstrable progress has been made against the actions originally identified in the ASD Strategic Action Plan’ (ibid., p.5). It also found that new areas (collaborative projects, housing needs, an evaluation of diagnostic services) had arisen in that period and were now included in the overall development of the Action Plan; particular reference was made to the establishment of a research agenda in Wales, with the appointment of a Professorial Chair in Autism in Wales (believed to be the first of its kind in the UK) and the foundation of a dedicated research centre (Wales Autism Research Centre) at Cardiff University.

2.5.2. The Scottish Strategy for Autism. (Scottish Government 2011) (99 pages)

The Scottish Strategy for Autism was written with lifespan perspective and laid out the longer-term aims for service development across a 10-year time span. The initial two-year focus (‘Foundations’) was on improvement in mainstream services and diagnoses. The next phase (‘Whole life journey’) aimed for integrated service provision across the life course of an individual with effective transition planning. It sought to develop the final phase of ‘Holistic personalised approaches’ within 10 years from the launch, and envisaged ‘creative and

collaborative use of service budgets to meet individual need' (p. 11) and close partnership working with the voluntary/independent sector. It made 26 recommendations under six key themes:

1. Strategic leadership,
2. Best value for services,
3. Collaboration and involvement in decision making,
4. Cross agency working through stronger networks,
5. High quality diagnosis, intervention and support, and
6. Wider opportunities.

2.5.3. Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum. (National Institute for Clinical Excellence [NICE], 2011) (57 pages).

NICE guidelines provide influential advice for health and social care providers in the United Kingdom. This document was published in 2011 and reviewed and published without amendment in 2014. It defined the key diagnostic features of autistic spectrum disorders (in line with International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders DSM-IV), 'a behaviourally defined group of disorders, which is heterogeneous in both cause and manifestation' (p. 4).

The guideline was written for practitioners and as such contains detailed diagnostic criteria and discussed related medical or psychological conditions. The report notes that 'approximately 70% of people with autism also meet diagnostic criteria for at least one other psychiatric disorder' and that a learning disability (defined here as having an intelligence quotient [IQ] below 70) is present in approximately 50% of young people with autism (ibid.).

Key recommendations are based on principles of patient centred care, i.e. the needs and views of children and parents should be taken into consideration, and information should be easily accessed and be culturally appropriate. Among the priorities identified was the need for local diagnostic pathways with a multi-agency strategy group and multidisciplinary autism teams. An individual case co-ordinator should be in place for every child undergoing diagnosis. Data collection, and where appropriate, sharing, should be facilitated. The report set out the steps that should be involved in referral and diagnosis, and highlighted the need for communicating findings with sensitivity.

The guideline listed factors that contribute to an increased prevalence of autism, including premature birth, neurodevelopmental disorders (such as cerebral palsy), chromosomal and genetic disorders (such as Fragile X syndrome) and having a sibling with autism.

Among the recommendations is the need to consider children under three years of age who show language or social skills regression. 'Watchful waiting' is considered an option that can be offered if initial assessments are inconclusive, or if the parents or child prefer not to go forward for diagnosis. Diagnosis should start no later than three months after referral. A follow up meeting should be held after six weeks of a diagnosis to discuss the findings. Families should have access to appropriate information and support, although the kind of support offered is not specified; the guidelines simply list possible sources, such as local or national support groups and organisations that offer benefits, educational support and social care advice.

2.5.4. Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum. (National Institute for Clinical Excellence [NICE], 2012) (56 pages).

This NICE guideline was issued in 2012 and reviewed and re-published without amendments in 2014. It sets out the key features of autism and possible co-existing conditions, such as sensory sensitivity learning disabilities and issues with behavioural flexibility. Key recommendations include a person-centred approach, a diagnostic procedure that recognises the range of social difficulties an adult may present with, such as problems in obtaining or sustaining education or employment, as well as neurodevelopmental indications.

Interventions should include supported employment where appropriate. Training for staff should include awareness of the need to make adjustments to the clinical environment where necessary (such as lighting, personal space, and noise levels), and the need for support for those individuals with autism who also have caring responsibilities. Appropriate psychosocial (social, life and anger management skills) and biomedical interventions were outlined, as well as interventions that should not be used, such as chelation, secretin, hyperbaric oxygen, exclusion diets and facilitated communication. Psychosocial interventions for challenging behaviour should be based on behavioural principles following functional analysis. The report also recommended that specialist autism teams should support individuals with autism in making and maintaining contact with housing, education and employment services, and residential home staff should be appropriately trained.

2.5.5. The management and support of children and young people on the autism spectrum.

(National Institute for Clinical Excellence [NICE] in collaboration with the Social Care Institute for Excellence, 2013) (36 pages).

This document outlined the key features of autism and set out working practice guidelines for transition and continuity of care. Its key recommendations included full access to health and social care for children with ASD, training for adequate standards of knowledge and competency of professionals, anticipation and prevention of behaviour that challenges (which should be based on a functional assessment of behaviour) and the involvement of young people in decision making, as well as services for parents and carers. These NICE guidelines also identified interventions that should not be used (such as secretin, chelation and hyperbaric oxygen treatment); areas for future research, including the role of key workers, parent training, sleep disorders and anxiety were highlighted.

NICE guidance for managing challenging behaviour and learning disabilities were at the consultation stage (NICE 2014). Once published, these guidelines will also have relevance for individuals with autism.

2.5.6. The Autism Toolbox: An Autism Resource for Scottish Schools. Scottish Government.

Based on the amended version of the original report of the same name (National Centre for Autism Studies 2009) (224 pages.)

The Autism Toolbox (www.autismtoolbox.co.uk) was launched by the Scottish Government in 2009 and intended as a resource for mainstream schools for teachers who aim to support pupils with ASD. Information provided included sections entitled Understanding Autism, Supporting Pupils, Whole School Planning, Supporting Well-being, Interventions, Partnership with Families, Working with Others and a range of resources.

The section on interventions was found to be based on misleading and very dated references and, following a legal challenge (Govan Law Centre) on the basis that the Scottish government was potentially acting unlawfully by distributing inaccurate information, Section 5: 'Overview of Interventions' was withdrawn in 2010. The webpage was designed and re-published in April 2014; this time, behaviour analysts were included in the revision team.

This development serves as an example that the exclusion of appropriately qualified behaviour analysts ((BACB, 2014) from the preparation of significant reports and reviews on autism not only prevents public access to accurate information on effective interventions, but erodes public confidence and can have detrimental consequences for statutory bodies as well as care provision.

An evaluation of interventions section is to be undertaken in 2015 by the Scottish Intercollegiate Guidelines Network (SIGN).

2.5.7 Reports from the Republic of Ireland.

2.5.7.1 Educational Provision and Support for Persons with Autistic Spectrum Disorders: the Report of the Task Force on Autism (Department of Education and Science 2001) (383 pages).

The Task Force on Autism was initiated by Dr Michael Woods, Minister for Education and Science in the Republic of Ireland (ROI), in October 2000, although the terms of reference make clear that it was intended to be an independent review. As with the concurrent Task Group in NI (2002, see Section 2.1), a representative from the respective Department of Education in each jurisdiction was a member of both review bodies. The panel did not include behaviour analysts, which led to the incorporation of misleading information about behavioural interventions.

The remit of the Task Force was to review the range of educational provision and support services for children with autism in ROI at that time, and to determine their effectiveness. The report is lengthy, and consists of 19 chapters (which include a review of then-current legal issues including the landmark Sinnott case, 14.1.3, and a section on cost-benefit analysis of existing provision, 16.4). Chapters 2-16 contain the main findings and relevant recommendations of the review panel; the current situation was deemed to be untenable and the Task Force stated that at the time of writing, services were ‘critically unable to meet the needs of all children with ASDs in Ireland’ (p.2).

The report concluded with a detailed list of all 183 recommendations by chapter, subdivided into ‘policy’ and ‘practice’. In summary, the recommendations for the education and welfare of children with ASD included

- The need for early identification and assessment
- The creation of a range of provision to meet individual needs (identifying ABA as one of two main approaches)
- Effective procedures to monitor such provision
- Prioritisation of mainstream education
- Partnership working with parents
- Multi-disciplinary approach to service delivery
- Appropriate training for all staff
- The need to fund research into the effectiveness of interventions and the prevalence of ASD in ROI
- A cost-benefit analysis of ‘early and on-going educational intervention for persons with ASDs’

The right to an inclusive educational setting was later reinforced by Section 2 of the Education for Persons with Special Educational Needs (EPSEN) Act of 2004 (DESS 2014).

2.5.7.2. A National Survey of Public Attitudes to Disability in Ireland. Disability Research Series 14. (National Disability Authority [NDA] 2011) (102 pages).

In June 2011, the National Disability Authority in the Republic of Ireland commissioned a national survey on public attitudes to disability. The resultant survey was one of a series conducted by the National Disability Authority over the previous 10 years (in 2001 and 2006 respectively), The results were based on a representative sample of 1,039 adults (aged 18+), with the addition of what the report described as a ‘ booster sample’ of 256 people with disabilities (p. 20). Interviews were conducted on a face-to-face basis in respondent’s homes and the survey was based on a final sample of 1,304 interviews (ibid.).

Autism was included in some response categories for the first time in 2011 (p.32, 42), but not as a distinct category in itself. Findings were frequently negative, in that e.g., the majority of the population surveyed (59%) agreed or strongly agreed that people with ‘intellectual difficulties or autism’ could not participate fully in life, while only a minority (38%) agreed or strongly agreed that children with these conditions should be educated alongside children without disabilities. Of those surveyed, only about half (51%) agreed or strongly agreed that people with intellectual disabilities or autism have a right to fulfilment through sexual relationships and only 37% felt they should have children, if they so wished and a breakdown of reasons for this indicated concerns primarily about child welfare. On a more positive note, in general, people were ‘comfortable’ with the idea of neighbours with intellectual difficulties or autism.

The conflation of autism and intellectual difficulties within categories makes it difficult to draw conclusions about public attitudes to individuals with autism, unlike the 2012 NI Life and Times survey, which included an autism-specific module (Dillenburger, Jordan & McKerr, 2012; See also BASE Project Report Vol.2).

2.6. Current cross-departmental policies in NI

The two most recent key cross-departmental initiatives introduce significant changes in relation to poverty and inclusion for individuals with autism and their families: Delivering Social Change Initiative (2012) and the Autism Strategy (2013-2020) and Action Plan (2013-2016).

2.6.1 Delivering Social Change

The Delivering Social Change framework was set up by the NI Executive (OFMDFM 2012) with the over-arching aim of addressing the problems of poverty and social exclusion through cross-departmental initiatives. It was viewed as a life-span framework, although a major focus was the need to address the health and wellbeing of children and young people and improving their life opportunities. The initiative sought to build on existing work, while focussing on a number of ‘signature projects’ that were expected to deliver meaningful outcomes.

Strategies that arose through this framework were expected to address the government’s obligations regarding the United Nations Convention on the Rights of the Child (UNICEF, 2006) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). It was managed through a structure of two sub-committees, supported by the Delivering Social Change Project Board, which met regularly to monitor progress (OFMDFM 2014a).

The Delivering Social Change Fund was established to support three initiatives: the Social Investment Fund, Improved Childcare, and the Delivering Social Change ‘signature programmes’ (OFMDFM 2014a). Initially six signature programmes were announced in October 2012, with an allocation of £26 million (AQW 19679/11-15). These were:

- Accelerating Social Enterprise
- Community Family Support Programme
- Direct Family Support
- Improving Literacy and Numeracy

- Nurture Units
- Support for Parents

A seventh programme (Play and Leisure) was announced in October 2013 (Hansard 2013).

In September 2014, the First Minister announced a further investment of £58.45 million (which included £24.65 million from Atlantic Philanthropies) for three new Delivering Social Change programmes

- Early Intervention Transformation Programme (EITP)
- Shared Education Programme (SEP)
- Dementia services (NI Executive 2014).

The initiative did not specifically address any issues around autism, although the post-consultation report recommended the adoption of wider outcomes to include ‘targeted services’ for children with special needs, as well as a more inclusive strategy for those from minority ethnic communities and people with disabilities (OFMDFM 2014b, p. 84-85).

However, some the signature projects, such as early intervention for behaviour problems, family support, play and leisure, reducing the numbers of young people not in education or training and accelerating social enterprise (OFMDFM 2014a,b) were of particular relevance to individuals with autism. In the meantime, the signature projects await full evaluation, although they have already been criticised for the lack of consultation with experienced practitioners, researchers, and organisations (e.g., Universities) prior to setting up the projects, that could have ‘assisted the Departments in identifying realistic, timely and measureable outcomes’ (OFMDFM, 2013).

2.6.2 The Autism Strategy (2013-2020) and Action Plan (2013-2016). (Northern Ireland Executive, 2014) (155 pages).

Mandated by the Autism Act (NI) 2011 and following a public consultation (December 2012-March 2013), the Minister of Health, Social Services and Public Safety launched the cross-departmental Autism Strategy (2013-2020) and the first Autism Action Plan for 2013-2016 in January 2014.

The strategy was the result of a joint initiative by 12 government departments, and detailed the scope, vision and values of the Strategy (Section 1). It examined the legislative background to the Strategy and analysed existing service provision across Health, Education, Employment and

Learning, Social Development, Justice, Arts and Culture (Section 2). It set out a number of Themes and Strategic Priorities (Section 3) and an implementation approach (Section 4) and concluded with the first Action Plan covering 2013-2016 (Section 5), based on these priority areas. The appendices contained a report on the prevalence of autism in school children in NI (2013) compiled by the NI Statistical Research Agency (NISRA; DHSSPS, 2014).

There were 11 Themes, each with at least one Strategic Priority that formed the framework for the action points in that area.

1. **Awareness:** The two strategic priorities were: to promote ‘front-line’ staff training and raise awareness generally.
2. **Accessibility:** There were three strategic priorities: improving travel and transport, better ‘signposting’ of information, and provision of advocacy services.
3. **Children, Young People and Family:** Three strategic priorities: providing ‘joined up’ support for families, increasing awareness of services, and providing support for carers.
4. **Health and Wellbeing:** The three strategic priorities were: improving access to health and well-being programmes, to ‘enhance and promote’ early recognition and intervention, and to implement best practice through reviews of services.
5. **Education:** There were four strategic priorities: building capacity in schools, supporting parental involvement, formalising joint working with the Health and Social Care sector and expanding trans-disciplinary assessments, and support for those children with complex needs.
6. **Transitions:** There were two strategic priorities: to ensure transition planning included the specific needs of individuals with autism, and the provision of co-ordinated ‘seamless’ arrangements.
7. **Employability:** There were two strategic priorities: to increase awareness of support provision and to promote employment/training opportunities for individuals with autism.
8. **Independence, Choice and Control:** There were four strategic priorities: to provide independent living options, information on the impact of proposed Welfare Reforms, to encourage ‘self-directed’ support within Health and Social Care, and to set up a pilot scheme for a multi-agency autism service.
9. **Access to Justice:** There were four strategic priorities: to provide information and support for those with autism who come into contact with the Justice system, to improve services for victims and witnesses to include the needs of those with autism, to review guidance for professionals, and to increase their awareness of autism.
10. **Being Part of the Community:** The strategic priority was to increase awareness about involvement in community activities for those with autism and their families.
11. **Participation and Active Citizenship:** The strategic priority was to involve individuals with autism in policy development in all government departments.

The Action Plan (2013-2016) set out a framework for implementation under each of these headings, mapping key actions, outcomes/performance indicators, designation of responsibilities, and timescale. The first of these actions (including funding for an awareness

campaign, improved signposting of services and a scoping study of services for siblings) were due by March 2014.

The Strategy required that an initial report should be produced for the NI Assembly by December 2016, and the Regional Autism Coordinator (the chairperson of the Autism Strategy Multi-Agency Implementation Team) was to prepare an annual report on the implementation of Autism Strategy Action Plans. In addition, five Local Autism Reference Groups from Local Autism Fora (Western, Southern, Northern, South Eastern and Belfast areas) were to be formed to provide user feedback on the Action Plans. However, in his address to the Assembly for the launch of the Strategy (Poots, 2014), the Minister made it clear that there would be no additional funding and initially at least much of the action plan was to be delivered using existing resources.

Conclusions

Since the publication of the Task Group Report on Autism (2002), a plethora of reports and initiatives on ASD and learning disabilities have been published in NI. In addition, there are a number of on-going reviews of education, health and poverty policies that will have implications for individuals with ASD. The focus of most of these was on ‘helping the most vulnerable out of the poverty trap and reducing inequalities’.

While the reports reviewed here (Section 2), written over a 12 year period, at considerable public expense, evidenced increasing awareness of the needs of individuals with ASD and outlined ambitious targets, the research literature reviewed in Section 1 and the perceived need for the Autism Act (2011) evidenced the disconnect between real life experience and rhetoric. This disconnect was also reflected in findings of the BASE project (Vol. 2-4).

Of particular concern throughout the review of reports was the emphasis placed on ‘early intervention’. Despite the frequent references to the importance of early intervention for young children with autism, in the initiatives and reports described in Section 2 of this report (and indeed for disadvantage and learning disability in general), the definition of *Early Intervention* remains unclear.

Advice on what constitutes appropriate early intervention varies from the very general (in the CYPSP report of 2011, see 2.4.15) to specifically identifying effective behaviour analysis-based

programmes, such as Early Intensive Behavioural Intervention (EIBI) within the research literature discussed in Section 1.

However, even the EITP programme delivered under Delivering Social Change programmes, does not include any provision for Early Intensive Behavioural Intervention (EIBI) or any of the other interventions that are based on the science of behaviour analysis (e.g., Early Start Denver Project). Instead, decisions are left to local providers, which means that there is still no common evidence-based approach, province wide, for early behavioural intervention for children with autism. Furthermore, there is no guidance on interventions that focus on common co-occurring medical conditions.

Responsibility for provision of suitable interventions for pre-school children lies both with Department of Health (e.g., through the Six Steps pathway and the Delivering Social Change Initiative) and Department of Education (e.g., through the early years education programmes and the Pre-School Education Advisory Groups (PEAG)). However, despite the endorsement of early intervention in general, the availability of autism-specific interventions and placements for pre-school children remains very low.

Early intensive behaviour analysis-based interventions are still not offered by statutory bodies (DENI, 2002). In some instances parents consider moving house to access these services, e.g., they move to the USA (Dillenburger & McKerr 2011), while in many other cases one parent leave their gainful employment in order to get trained themselves and organise home-based early ABA programmes, that are supervised by a voluntary organisation (Dillenburger et al., 2010). Clearly, this adds to the potential of living in poverty for these children and their families.

Emerging Key Themes

Since 2002, there has been a keen awareness of shortfalls in service provision to address the issues that contribute overall to poverty and lack of inclusion for children and adults with autism. Key to this has been a reluctance to embrace evidence-based early behavioural interventions, that are based in the science that has been identified as providing the most rigorous data of evidence based interventions, applied behaviour analysis (ABA) (Keenan et al., 2014). The exclusion of experts in the science of behaviour analysis (e.g., NI academics) from policy and strategy, despite the acknowledged lack of expertise in this area in the statutory sector (DENI,

2002), has led to hesitancy of the sector to embrace international best practice in autism intervention (National Autism Center (NAC), 2009).

Given the clear message in all policy and strategy documents published since 2002 about the importance of early intervention, the key message from this literature review is that in order to achieve full economic and social inclusion for people with autism and their carers, effective early intensive behaviour analysis-based intervention need to be embraced. This will lead to better educational achievement, better social and independent living skills, and better employment prospects (for adults with autism and their caregivers). Of course, any co-occurring medical issues, such as epilepsy, allergies etc. need to be addressed at the same time.

This literature review identified the existing research database and pointed towards international best practice of how to help the most vulnerable out the poverty trap and reduce inequality and thereby saving considerable social, emotional, and fiscal resources.

Recommendations:

1. ***Collaborative working*** across departments and service sectors with a focus on provision of and access to services and activities (including education, sport and leisure, housing, employment).
2. ***Financing*** and transparency of budgets between children and adult disability services;
3. ***Parental and advocate involvement*** in autism specific initiatives to ensure that service user voices are included in future development.
4. ***Effective, evidence-based interventions*** of international standards based on the science that has been identified as providing the most rigorous data for evidence-based interventions, applied behaviour analysis (ABA); rather than an eclectic mix of interventions, that are not based on evidence.
5. ***Expertise of staff delivering services*** including re-training of existing staff (e.g., fully utilising/commissioning internationally approved training in applied behaviour analysis and autism offered at local Universities) and/or the targeted employment of Board Certified Behaviour Analysts.
6. ***Adults with ASD*** included in policy and decision making with a clear focus on diagnosis and services for adults, including where possible, self-directed autism services.
7. ***Transition processes and employment*** and post-19 education or social care settings improved.

8. *A comprehensive database* on prevalence of autism (for children and for adults) and uptake of services.

Ultimately, unless these recommendations are translated into tangible actions, the most vulnerable in NI, will remain in the poverty trap and inequalities will not be reduced.

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Appendix 1: NI ASD-specific initiatives and reports

'02	'03	'04	'05	'06	'07	'08	'09	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	'20									
█																		Task Group Report (DENI)									
█																											ASD A Guide to Classroom Practice (DENI)
				█															Mental Health & Learning Disabilities: ASD (Bamford)								
					█														Meeting the Needs of Families (UU/QUB/ RIA)								
						█													Review of Needs and Services (University of Birmingham/ NICCY)								
							█												'I Exist' (National Autistic Society[NAS])								
								█											Improving Services for People with ASD (NIA)								
									█										Independent Review of Autism Services (DHSSPS)								
										█									ASD Action Plan 08/09-09/10 (DHSSPS)								
											█								Is Anyone Listening? (AutismNI)								
												█							Employing People with Autism (NAS)								
													█						Six Steps of Autism Care (RASDN/HSCB)								
														█					Autism: A Guide for Families (RASDN/HSCB)								
															█				Autistic Spectrum Disorder Transitions Guidance (RASDN/HSCB)								
																█			Autistic Spectrum Disorder Support: Along the Lifespan (RASDN/HSCB)								
																	█		Trust Performance Reports (RASDN) (annual)								
																			Autism Act (NI)								
																			A* is for Autism (NAS)								
																			Autism: Adult Care Pathway (RASDN/HSCB)								
																			Autism Strategy (NI Executive)								
																			Autism Action Plan (NI Executive)								
																			Autism: A Guide for Criminal Justice Professionals (NAS/DoJ)								

Publication/lifespan
 Presumed continuation

Appendix 2: Other relevant NI reports

'02	'03	'04	'05	'06	'07	'08	'09	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	'20	
																			Supporting People (NIHE)
																			Equal Lives (Bamford Review)
																			The Special Educational Needs and Disability Order (SENDO)
																			A Healthier Future 2005-2025 DHSSPS
																			Report of Transitions Interdepartmental Working Group
																			Our Children & Young People Our Pledge (OFMDFM)
																			Promoting Collaborative Working SEN (DENI, ETI, DHSSPS)
																			Disability Action Plans (3) (DEL)
																			Lifetime Opportunities (OFMDFM)
																			CAMHS Vision (Bamford Review)
																			Inclusion (Bamford Review)
																			Audit of Day Services (DHSSPS)
																			Bamford Mental Health & Learning Disability Action Plans (2) (DHSSPS)
																			Delivering the Bamford Vision (DHSSPS)
																			What the Future Holds (QUB/ Changing Ageing Partnership)
																			Evaluation of Transition Arrangements (ETI)
																			Every School a Good School Consultation (DENI)
																			Manifesto (Children with Disabilities Strategic Alliance) [CDSA]
																			Families Matter (DHSSPS)
																			Lifetime Opportunities Monitoring Report (OFMDFM)
																			Transition to Adulthood Action Plan (CYPSP)
																			NI Children & Young People's Plan (CYPSP)
																			Children & Young People Action Plan (DARD)
																			Further Education (Bamford Monitoring Group)
																			My Day, My Way (Bamford Monitoring Group)
																			Evaluation Bamford Action Plan 2009-2011 (DHSSPS)
																			Supporting People With Intellectual Disabilities (UU/PHA)
																			Barriers to Effective Government Delivery (NICCY)
																			Service Framework for Mental Health & Wellbeing (DHSSPS)
																			Transforming Your Care (Compton report) (DHSSPS)
																			Programme for Government (NI Executive)
																			Childcare for All? (Employers for Childcare)
																			Review of the Youth Justice System. Department of Justice
																			Childcare Across the Lifespan (QUB/ OFMDFM)
																			Improving Children's Life Chances (NI Executive)
																			Speech, Language & Communication Action Plan (DHSSPS)
																			A Strategy to Improve the Lives of Disabled People (OFMDFM)
																			Summary Report of Responses to ESaGS Consultation (DENI)
																			Review of SEN and Inclusion (policy development) (DENI)
																			Improving Children's Life Chances Annual Reports (2)(NI Executive)
																			Every Child an Equal Child Equality Indicators (Equality Commission)
																			Monitoring Poverty and Social Exclusion (Joseph Rowntree Foundation)
																			Manifesto Review and Update (CDSA)
																			Review of Transitions to Adult Services (QUB/NICCY)
																			Access to Success (DEL)
																			Fit and Well 2012-2022 (DHSSPSS)
																			Don't Box Me In (QUB/Barnardo's)
																			Impact of Transition on Family Life (Post-19 Lobby Group)
																			Who Cares? The Future of Adult Care (DHSSPS)
																			Service Framework for Learning Disability (DHSSPS)

 Publication/lifespan (autism references)

 Publication/lifespan (no autism references)

