



Northern Ireland
Assembly

Research and Information Service Briefing Paper

Paper 41/15

24 October 2014

NIAR 645-14

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The Provision of Services for Children with Autism

This paper provides the legislative background to the provision of autism services in Northern Ireland. It outlines the current range of services provided by the Department of Education and highlights issues in the provision of educational services relating to autism. Finally, the paper lists organisations involved in autism education in Northern Ireland.

1. What is Autism?

Autism is a lifelong disability which affects the way an individual relates to people, situations and their immediate environment. The term Autism Spectrum is often used because the impact of autism varies from person to person.¹

The National Autistic society notes that “Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support”.²

The National Autistic Society provides more details at the following URL:
<http://www.autism.org.uk/>

2. Legislative Context of Autism Service Provision

2.1. United Nations

In 1989, governments promised all children the same rights by adopting the United Nations Convention on the Rights of the Child. The convention acknowledges that children have the right to express their opinions and to have those opinions heard and acted upon when appropriate.³

Signatory countries of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2008) are obliged to:

*“promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity”.*⁴

2.2. The Disability Discrimination Act

The Disability Discrimination Act 1995 is anti-discrimination legislation which specifically focuses on people with disabilities. It places duties on employers, service providers, landlords, schools and colleges. Part 3 of the Special Educational Needs and Disability (NI) Order 2005 focuses specifically on disability discrimination in education.⁵

The Disability Discrimination Act 1995 was strengthened by the Disability Discrimination (NI) Order 2006; public bodies are required, when carrying out their statutory functions, to have due regard to the need to:

¹ The Northern Ireland Executive *The Northern Ireland Autism Strategy 2013-2020*:

www.dhsspsni.gov.uk/autism-strategy-action-plan-2013.pdf

² National Autism Society Website:

www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx

³ The Northern Ireland Executive *The Northern Ireland Autism Strategy 2013-2020*:

www.dhsspsni.gov.uk/autism-strategy-action-plan-2013.pdf

⁴ United Nations Enable website: <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁵ www.legislation.gov.uk/nisi/2005/1117/contents/made

- Promote positive attitudes towards people with disabilities; and
- Encourage the participation of people with disabilities in public life.

2.3. The Children (NI) Order

The Children (NI) Order 1995 relates to children with special needs:⁶

- Article 17 states that a child shall be taken to be in need if “he is disabled.”
- Article 18 determines the statutory responsibilities of HSC Trusts to provide for ‘children in need’ in their area, including disabled children.
- Article 19 provides for support for ‘children in need’ within early years, which also includes children with disabilities.

2.4. The Autism Act Northern Ireland

The Autism Act (NI) 2011 is based on equality and rights. It aims to ensure that people with autism have the same entitlements and opportunities as those with other disabilities. It also requires the Government Departments in Northern Ireland to collaborate to provide services for people with autism and their carers.⁷

The Autism Act amends the definition of a “disabled person” contained within the Disability Discrimination Act 1995. The amended definition applies exclusively to Northern Ireland. Preceding the enactment of the Autism Act, impairment was defined as affecting a person’s ability to carry out normal day to day activities, only where one of the following was affected by the impairment in question:

- Mobility;
- Manual dexterity;
- Physical co-ordination;
- Continence;
- Ability to lift, carry out or otherwise move everyday objects;
- Speech, hearing or eyesight;
- Memory or ability to concentrate, learn or understand; or
- Perception of the risk of physical danger.

⁶ Legislation.gov.uk: www.legislation.gov.uk/nisi/1995/755/contents/made

⁷ The Law Centre Northern Ireland: www.lawcentreni.org/

The Autism Act extends the list of criteria, adding the following activities;

- Taking part in normal social interaction; or
- Forming social relationships.

The Act also clarifies the legal position, ensuring that people with social and/or communicative disabilities are afforded the protection of the Disability Discrimination Act 1995. This amendment requires Health and Social Care (HSC) Trusts to ensure that all existing policies, practices and procedures are compliant with the requirements of the amended Disability Discrimination Act 1995.

3. Service Provision

There is a range of autism related educational services: mainstream schools, special schools and 'resource bases' allocated to mainstream schools.⁸ Appendix 1 outlines the Minister of Education's response to an Assembly Question on service provision for children with autism in Northern Ireland.

The Department of Education provides core funding annually to the Education and Library Boards for all Special Educational Needs, including autism. The Executive's 2013- 2020 Autism Strategy states that, since the 2003/04 financial year, the Department of Education has provided £17m of additional resources to support various measures specific to autism. This figure is in addition to SEN core funding.⁹ The resources provided include:

- Autism related training within the pre-school sector;
- The publication of "Autistic Spectrum Disorders – A Guide to Classroom Practice" for teachers in all schools;
- The production of a range of school/parent resources to support positive interventions for children with autism;
- The publication of 'Evaluating Provision for Autistic Spectrum Disorders in Schools';
- The Inter-board Autism Group; and
- The Middletown Centre for Autism.

The Department of Education published a Special Educational Needs (SEN) Resource File for schools in 2011. It contains practical materials to help teachers support pupils with SEN. A specific chapter is dedicated to autism support. During 2013, a self-study

⁸ The National Autistic Society (2006) *Make School Make Sense Autism and Education: the reality for families today*

⁹ The Northern Ireland Executive *The Northern Ireland Autism Strategy 2013-2020*:
www.dhsspsni.gov.uk/autism-strategy-action-plan-2013.pdf

module (ASPIRE) was supplied to schools to help build their capacity in using the SEN Resource File.¹⁰

Inter-board Autism Group

The Inter-board Autism Group was established in 2003/04. It aims to promote consistency in relation to the identification, assessment and delivery of services across the five Education and Library Board (ELBs). This led to the establishment of an autism advisory team in each ELB. The teams are comprised of a specialist senior educational psychologist, advisory teachers and other autism support officers.¹¹

Middletown Centre for Autism

Established in 2007, the Middletown Centre for Autism provides training and research services and is funded jointly by the Department of Education and the Department of Education and Skills in the Republic of Ireland.

Its services are designed to be complementary to those provided by the ELBs. The centre trains professionals and parents, provides interventions for children and helps schools develop an autism competent environment.

The education inspectorates of Northern Ireland and the Republic of Ireland carried out a joint inspection of the Centre in 2012. The quality of the provision was evaluated as being outstanding.

4. Strategy

The Autism Action Plan (2013-16)

The details of the Northern Ireland Executive's Autism Action Plan (2013-16) relating to education can be found in Appendix 2.

The SEN and Inclusion Review

During 2012, the Executive agreed to a revised policy for SEN and Inclusion and to the preparation of a Bill amending the existing legislation. The key objectives include early identification, intervention and assessment. It also aims to ensure that the needs of all children and young people with SEN (including those with autism) are met.¹²

5. Key Issues in Provision of Autism Education Services

Children with autism need an education that allows them to acquire the skills, knowledge and understanding that other children acquire intuitively.¹³ Given the diversity between individuals, there is no single educational intervention that is suitable

¹⁰ The Northern Ireland Executive The Northern Ireland Autism Strategy 2013-2020: www.dhsspsni.gov.uk/autism-strategy-action-plan-2013.pdf

¹¹ The Northern Ireland Executive The Northern Ireland Autism Strategy 2013-2020: www.dhsspsni.gov.uk/autism-strategy-action-plan-2013.pdf

¹² Department of Health, Social Services and Public Safety Website: www.dhsspsni.gov.uk/asap-section2-8-4

¹³ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

for meeting the needs of all children on the autism spectrum. There is, therefore, an issue as to how appropriate access to resources is achieved for every child.¹⁴

The National Autistic Society Northern Ireland carried out a survey of children with autism and their parents.¹⁵ Their report, published in 2012, highlighted the following issues:

- More than one in four young people said they don't feel happy at school;
- One in five of the young people surveyed don't feel safe;
- One in three children surveyed have only one friend, or no friends at all;
- 80% of the pupils indicated that they want to have friends;
- A quarter of young people responded that one of the worst things about school is being picked on;
- Almost one third of young people responded that one of the worst things about school is teachers not understanding them;
- Half of parents indicated that they feel their child is making good educational progress;
- Almost one in three parents feels that the education their child receives is not adequate to their needs;
- Just less than half of parents are satisfied with the support their child receives at school.

Timely Support

The National Autistic Society Northern Ireland (NASNI) report¹⁶ advises that nearly 2 in 3 of the parents surveyed said that getting support for their child had not been easy. Over half of parents who took part in the survey waited over a year from when concerns were first raised until they received appropriate support. Nearly one quarter of those surveyed waited over two years, whilst one in ten children waited more than three years.

Appropriate Support

In Northern Ireland children with autism are educated in one of the following:

- mainstream school
- specialist autism unit attached to a mainstream school

¹⁴ Autism Education Trust (2008) *Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges*

¹⁵ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

¹⁶ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

- learning support unit or a generic special school

Children who have autism and additional learning difficulties are more likely to attend a special school. Special schools are often further away than a local school. Also, many special schools are designed to cater for a wide range of special educational needs. Many of these needs are non-autism issues, meaning that educational compromises need to be made.¹⁷

It is argued that parents in Northern Ireland need better information and advice about the educational options available.¹⁸

Exclusions and Suspensions

The NASNI reports that it is common for parents to be asked to take their child out of school because the school would not or could not cope with the child's behaviour.¹⁹

Staff Training

The research carried out by NASNI indicates that expertise in schools remains patchy. The report argues that many teachers do not get the training, knowledge or resources that they need to help children with autism. Almost one in five parents indicated dissatisfaction with teacher understanding of how to support children with autism.

Bullying

Over 40% of parents who replied to the NASNI survey said their child had been bullied. Over a quarter responded that they were not sure if their child had been bullied or not.²⁰

Classroom Assistants

Classroom Assistants are typically hired by the school but funded by the Education and Library Boards. In an answer to a written question in 2011 the Minister for Education stated that the average cost of a classroom assistant can range from £7,175 in the North East Education and Library Board to £18,282 in the Western Education and Library Board.²¹

Mainstream Resource Base

An 'autism resource base' can be attached to a mainstream school. This happens when there is sufficient need for students to be removed partially from mainstream classes and educated separately in smaller groups.

¹⁷ Hutchinson S. (2014) "Special Needs Introduction" Available: <http://nia1.me/27c>

¹⁸ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

¹⁹ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

²⁰ The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

²¹ <http://nia1.me/279>

“My child has super support in an autism-base attached to a mainstream school - the staff and their expertise is exemplary. I feel very fortunate to have a place there. It was a struggle to find and be offered a place, but worth the fight.” Parent²²

Increased Diagnosis Rate

A recent study²³ has suggested that, in the period 2008-2014, the percentage of students on the autism scale has grown from 1.2% to 2.0%. Given the issues outlined in this document, the difficulty of dealing with a growing number of children with autism represents a challenge.

6. Organisations Involved in Autism Education

There are several Non-Governmental Organisations (NGO) and Charities that provide a wide range of educational support services in Northern Ireland.

Autism Network Northern Ireland

Autism Network Northern Ireland provides support for parents and carers for children affected by autism. It helps with SEN reviews as well as providing links to the various government services available.

Autism Northern Ireland

This organisation provides support, including training courses accredited by AQA. Courses are aimed at Social Workers, Classroom Assistants, Disability Sports Officers, Assistant Psychologists, Playgroup Assistants and Parents.

The National Autistic Society

The National Autistic Society provides extensive educational services, including training, specialist schools (In England and Wales), consultancy and social clubs. The services are based primarily in England but are available to professionals in Northern Ireland.

Parents' Education as Autism Therapists (PEAT)

This NGO offers training and services aimed at people who want to help those involved with working with people with autism. They deliver training in-house and offer services to schools and universities. In addition, they offer consultancy services similar to the National Autistic Society.

Autism Initiatives

This organisation offers training and consultancy in the form of their Outreach Education Support (OSSME) programme. The organisation aims to educate and train

²² The National Autistic Society (2012) *A* for Autism: Make Every School a good School*

²³ Department of Health, Social Services and Public Safety (2014) *The Prevalence of Autism (including Asperger's Syndrome) in School Age Children in Northern Ireland*

people who work with autistic children. They also run a school for autistic children, but this is based in Merseyside, England.

EAGLE – Belfast Central Mission

The EAGLE programme run by the Belfast Central Mission organises a number of services aimed at mostly families. One such programme is the Early Adolescence Project. This service aims to help children on the autism spectrum prepare for 2nd level education.

Appendix 1: Assembly Question 22/09/2014**AQW 36268/11-15 Mr Ross Hussey**

To ask the Minister of Education to detail the education services available in each Education and Library Board for children with autism.

Following publication of the 'Report of the Task Group on Autism' (2002), DE funded the Education and Library Boards (ELBs) to establish an inter-board Autistic Spectrum Disorder (ASD) Group to provide support to children on the autistic spectrum within each ELB. As a consequence, an ASD advisory team was established in each ELB to enhance existing ASD services.

The ASD advisory service provides valued and worthwhile practical support to schools and is a resource of knowledge and skill, with the capacity to raise the standards of education and the social inclusion for children on the autistic spectrum by providing tailored support to match the individual needs of each child to ensure that they reach their full potential.

The ELBs have also developed a comprehensive range of services and provision to support pupils with learning difficulties (including autism), their parents/carers and schools. ELBs also provide autism-specific training in schools and all ELBs deliver a range of autism-specific training for school staff.

Examples of support include:

Early Years

teaching support for children and parents in the home setting; this is organised on the basis of referral from either educational psychologists, community paediatricians, or multi-disciplinary teams;

advice, support and training to nurseries and some playgroups to support the child's effective inclusion in mainstream pre-school settings;

in some cases, children have statements of SEN in the early years. If this is the case, the child may access placement in a nursery with adult assistance, where appropriate, placement in a diagnostic setting, or placement in nursery class that is attached to a special school.

Primary Years

advice and support from learning support staff who can advise schools on individual education plans as well as strategies that may be appropriate for specific children;

outreach support and teaching from staff that are attached to special schools for children at stages 3,4 and 5 of the Code of Practice;

adult assistants, where appropriate, in mainstream schools for children who have statements of SEN;

access to placement in learning support classes that are attached to mainstream schools; this provides teaching in a small group placement with inclusion in mainstream classes, as appropriate;

placement in special schools that meet the needs of children and young people with SEN.

Post-Primary Years

The core areas of support include all the services offered at primary level and in addition:

access to transition services to support the planning of young people's needs as they transition from school to adult learning programmes;

access to counselling services as part of post-primary support; and

participation in a range of course options through the Entitlement Framework.

The Middletown Centre for Autism also provides a range of support and intervention to professionals, parents and children with autism. Parents can avail

of a range of training courses provided free of charge by the Centre and can access a broad range of online learning resources, including training video materials.

The Centre is also currently expanding its programme of direct support and intervention to children with complex autism who are referred to it by the ELBs.

Appendix 2: Education Section of the Autism Action Plan (2013-2016)

5 Education						
Strategic Priority						
<ul style="list-style-type: none"> Ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential. 						
Key Action	Action Summary	Outcome Required / Performance Indicator	Responsibility	Lead Responsibility	Timescale	
5a) Capacity Building for Schools and Youth Service	5.1 Continue to build the capacity of schools and youth service to meet effectively the needs of children and young people with autism	<p>5.1.1 Effective autism support, training programmes and research and information for schools provided.</p> <p>5.1.2 Potential explored for youth workers to have access to elements of support services deemed necessary, which are currently available to schools, to support young people with autism</p>	DE, ELBs/ESA, Middletown Centre for Autism (with support from HSCB / PHA, HSCTs)	ELBs/ESA	2013 – 2016	
	5.2 Provide parents/carers of children and young people with autism with effective support and advice which will ensure that they are informed, involved and supported effectively by the school, the ELB/ESA and other agencies.	<p>5.2.1 Effective autism support training programmes, research and information for parents and carers provided.</p> <p>5.2.2 Revisions to Middletown Centre for Autism's parent/carer training model scoped and developed and implemented.</p>	DE and ELBs Youth Service	ELBs Youth Service	2013 – 2016	
5b) Supporting parents/carers			DE, ELBs/ESA, Middletown Centre for Autism (with support from HSCB, HSCTs)	ELBs/ESA	2013 - 2016	Middletown Centre for Autism

5 Education						
Strategic Priority						
<ul style="list-style-type: none"> Ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential. 						
Key Action	Action Summary	Outcome Required / Performance Indicator	Responsibility	Lead Responsibility	Timescale	
5c) Support and provision for children and young people	5.3 Implement a common model of professional support and provision for children and young people with autism to meet their needs	5.3.1 Regional implementation plan for a common model of support developed.	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2014	
		5.3.2 Preparation for implementation of common model of support undertaken	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2015	
		5.3.3 Common model of support fully implemented	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2016	
5d) Support and provision for children and young people	5.4 Formalise protocols for collaboration between education and health autism services (including specialist services such as CAMHS).	5.4.1 Protocols scoped and developed.	ELBs/ESA, Middletown Centre for Autism, HSCB and HSCBs	Joint Lead ELBs/ESA and HSCB	September 2014	
		5.5 Expand educational-led trans-disciplinary assessments, support and intervention mainly for children and young people with autism presenting with more complex needs.	5.5.1 Increased number of children and young people with autism presenting with complex needs receiving support	DE, ELBs/ESA, Middletown Centre for Autism	Middletown Centre for Autism	2013 - 2015