

## National Autistic Society Northern Ireland

The National Autistic Society (NAS) Northern Ireland is the charity working throughout Northern Ireland for people affected by autism. In Northern Ireland we provide information, advice and support and campaign and lobby for lasting positive change for those affected by autism. We have twelve NAS branches in Northern Ireland, providing local sources of information and support.

NAS Northern Ireland delivers a number of services including:

- Our **help!** Programme which provides parents and carers of school-age children, young people and adults with post-diagnostic information, advice and support
- Our Befriending scheme which trains and supports volunteer befrienders to spend a few hours a week with an adult or child with autism or Aspergers syndrome or a family member
- Parent to Parent confidential telephone support service, provided by trained parent volunteers who have personal experience of autism and want to support other parents
- Our telephone based Advocacy for Education service, which provides information, advice and support on education provision and entitlements to help guide families through education law
- Support group for parents of adult children.
- Teenscene for young adolescents
- Our Social Groups are for over 16's with high functioning autism or Aspergers syndrome and meet once a month for social activities.
- Our team of family support workers who act as advocates for parents providing practical and emotional support.
- A range of social and leisure activities for children and adults with autism.

What is an autism spectrum disorder?

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty (sometimes known as the 'triad of impairments'<sup>1</sup>) are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist care. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. People with Asperger syndrome may not necessarily have learning disabilities but often have accompanying learning difficulties, including dyslexia.

We use the term autism here to cover all people on the autism spectrum, including autism, Asperger syndrome and other diagnostic terms used for autism spectrum

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<sup>1</sup> Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, Vol. 9(1), pp. 11-29

conditions. Over 17,000 people in Northern Ireland have autism if you count their families autism touches the lives of over 68,000 people. Despite this, autism is still relatively unknown and misunderstood. That means that many people affected by autism and their families get nothing like the level of help, support and understanding they need.

## **Overview of the involvement of the National Autistic Society in the Development of autism initiatives in England, Scotland, Wales and Northern Ireland**

The National Autistic Society was one of the *principal proponents* of the Autism Bill which became the Autism Act in England in 2009. We worked with 13 other autism organisations to take this forward. This resulted in the development of an Adult Autism Strategy in March 2010. Statutory Guidance for local authorities and health bodies is currently being consulted on.

In Scotland the National Autistic Society has pioneered an Autism Bill which is currently in the Scottish Parliament.

In Wales the National Autistic Society has been active in the development of the Autism Spectrum Disorder Strategic Action plan which sets out how services will be delivered to people affected by autism in Wales.

In Northern Ireland the National Autistic Society has been an active member of the Regional Autistic Spectrum Disorder Network (RASDN) which was formed to take forward the DHSSPS ASD Strategic Action Plan. The National Autistic Society Northern Ireland sits on the Reference Group, the adult subgroup, communications group and the Northern Trust ASD forum. We are also involved in the Transitions, Interventions and Training work streams.

### **Autism Bill NI**

#### **Background and policy Objectives**

The National Autistic Society Northern Ireland supports the main objective of the Autism Bill which is to enhance the provision of services to and support for people with Autistic Spectrum Disorders

## **Clause 2 the Autism Strategy**

The National Autistic Society Northern Ireland supports clause 2 of the Autism bill which requires all Northern Ireland Government Departments to co-operate in the development of an autism strategy and to implement any part of the strategy for which they are responsible.

### **Amendment to the Autism NI Bill**

Whilst the National Autistic Society Northern Ireland welcomes the intention for consultation between NI government departments we are concerned that the depth of knowledge and experience of people affected by autism and their parents/ carers and the voluntary sector will not be sufficiently considered if not outlined in the Bill. The National Autistic Society Northern Ireland suggests an amendment to the Bill which will outline their involvement in the process. The proposed amendment could be inserted in Clause 2 on page 1

- **The Department should establish a reference group comprised of people with autism, parents/carers, and representatives from the voluntary and statutory sector to develop the autism strategy and to oversee its implementation.**

## **Clause 3 – Content of the Autism Strategy**

### **Whole life support for people with autism**

The National Autistic Society Northern Ireland supports the content of the strategy in relation to requiring the lead Department to set out how the needs of people with Autistic Spectrum Disorders are to be addressed throughout their lives. Health and Social Care has started to address some of the historic deficiencies in the Health and Social Care sector in relation to autism. In June 2009 Minister Michael McGimpsey published the ASD Strategic Action Plan which arose out of the independent review of autism services which was chaired by Lord Maginnis.

The Minister commissioned the Regional Autistic Spectrum Disorder Network to take forward the implementation of the Strategy. Dr Bergin and Lord Maginnis head up this process. This has started to produce results.

## **Why we Need a Cross Departmental Strategy for Autism**

Below is a brief synopsis of current initiatives in relation to Autism and also an outline of areas that the National Autistic Society Northern Ireland believes would benefit from cross-departmental working.

### **Health and Social Care**

#### **Work of RASDN**

The National Autistic Society Northern Ireland is an active participant of the Regional Autistic Spectrum Disorder Network (RASDN). What is unique about RASDN is the involvement of parent/carers, people with autism, the voluntary sector and the statutory sector who are all working together to devise services that best meet the needs of people with autism and their families and carers. Parents and carers are officially mandated as advisors to the Reference Group and to each Trust. They are involved in all recent investments and in service improvement. RASDN is working well and we are starting to see outcomes from the Group

Some of the outcomes of the group include;

- Financial Investment in Autism Services £1.54 million over the 2009 -2011 an extra 100k announced (November 2010) which brings the recurrent total new investment to 1.64m from April 2011
- Development of the children's diagnostic pathway which will be implemented across all Trust areas
- A reduction in waiting lists re assessment to 13 weeks (four of the five trusts are now meeting this target. All Trusts should be compliant by March 2011.
- The recommendations for the Adult Diagnostic pathway will be available in January 2011
- Work streams are ongoing in Training, Interventions and Transitions
- Information resource to guide parents/carers and people with autism to relevant services and resources throughout their life.

The National Autistic Society Northern Ireland supports the work of this group and would suggest that any future strategy needs to ensure that this work is continued.

The National Autistic Society Northern Ireland recommends that any future strategy that arises from the Autism Bill should adopt the structure of RASDN (i.e. ensuring that parents, carers and people with autism the voluntary sector and the statutory sector are all actively involved in service design, improvement and investment). As outlined previously we have suggested an amendment to the Autism Bill to facilitate this.

RASDN is producing results in Health and Social Care but it does not have a remit over education or Employment and Learning although education is represented on the reference group..

## **Education**

The Department of Education is working on the production of an education strategy for children with autism. Recent proposed changes outlined in the SEN Review resulted in an unprecedented number of responses from concerned parents, many of whom were parents of children with autism. While the National Autistic Society Northern Ireland supports the production of an Education Strategy for children with autism we believe that it needs to work in tandem with the Department of Health and Social Services and the Department of Employment and Learning. We also believe that an Education Autism Strategy should be produced in conjunction with the voluntary sector and parents, carers and people with autism in the same way that RASDN works.

Education must ensure that the needs of children with autism are met; children with autism need specialised autism specific support if the best outcomes are to be achieved. Below a parent of a child with autism outlines her experience of the complexity of the condition and the need to provide specialised, well resourced support. It is a lack of resources which prevents the employment of a 1:1 assistant in this case.

*“My son is generally in good health. His language is reasonably good and he has a good vocabulary. However, he repeats the same things over and over again and insists that you listen intently. He has reasonably good relationships with family members but his unpredictable behaviour makes it difficult for him to sleep over with all but the closest family. He is very sociable but often approaches strangers. He seems to persevere with school more than enjoy it. He refuses to go to school at least twice a week and does not talk about his activities unless pressed. School have identified him as an excellent candidate for 1:1 support which they are unable to provide. His work is cut down so I believe that he is not accessing the full curriculum. He is a frustrated child. He does not understand why certain behaviours are not acceptable or are inappropriate. He has regular tantrums when things do not go his way. His behaviour is very unpredictable and going out always has the possibility of being cancelled if he puts himself or one of his siblings in physical danger. He tries very hard to follow rules but is regularly disappointed when he doesn’t manage it. Our main concern is that without support and assistance, he will never achieve his potential whatever that might be and that his mental state will continue to deteriorate as his peers move further and further away educationally.”*

Calls from parents to our Education helpline are often on the issue of what parents feel is a lack of understanding of ASD and the provision of specialist support. Below is a quote from a Parent outlining her experience of how a school has addressed the issue of autism.

*“A number of incidents have happened since the start of term. The school has dealt with these simply as incidents of bad behaviour. I feel that the problems are due to sensory issues which have not yet been understood or addressed. My son is beginning to say that he “hates school” and I am beginning to lose confidence in the school. I am starting to consider educating him at home”*

The quote below outlines the difference that appropriate specialised support can make to a child with autism.

*My son's educational needs are best met in a highly structured environment. The support he has received so far illustrates that his needs require a predictable, understanding environment. For reasons of health and safety and to enable my son to develop, he will require constant 1:1 adult support and supervision. The benefits of having support from adults with a good knowledge of autism spectrum disorders has been proven and is very obvious to us as parents.*

The National Autistic Society Northern Ireland believes that education plays a fundamental role in addressing the needs of children and young people with autism. To ensure effective intervention Education needs to develop its Strategy in conjunction with The Department for Health and Social Care and the Department for Employment and Learning. Children with autism often need to avail of Speech and Language and OT therapies within the school environment and these are often outlined on a child's Statement of Special Educational Needs, however there is no legal obligation for the Department of Health to provide these services.

### **Adults with Autism**

**Any Strategy that is produced must pay particular attention to the issue of adults with autism. The National Autistic Society Northern Ireland's I Exist research** found that Adults with autism are often unable to access the right support, and consequently often become dependent on their families. 75% of adults with autism rely on their families for financial support; only 13% live independently. 96% of the adults who took part in our research felt that with more support they would feel less isolated. As a direct result of this lack of support 34% of adults in our survey have experienced severe mental health difficulties and 57% suffered from depression. There has been a historic lack of funding for services for adults with autism and this needs to be addressed

Adults with autism also experience issues with regards to accessing employment and benefits.

### **Employment and Benefits**

In October 2009 **the National Autistic Society launched its Don't Write Me Off Campaign** which aimed to make the system for accessing employment and benefits



fairer for adults with autism. The report for the campaign surveyed a group of adults with autism across the UK and found that:

- One third are currently without a job or access to benefits
- Over half have spent time with neither a job nor access to benefits, some for over ten years
- Just 15% have a full time job
- 79% of those on Incapacity Benefit want to work
- 82% who have applied for benefits say they needed support to apply

In order to address the needs of adults with autism more needs to be done to ensure that adults with autism are able to get a job when they can work and benefits when they can't.

### **Awareness of Autism in Northern Ireland**

The National Autistic Society Northern Ireland supports the inclusion within the Bill of an awareness raising campaign on autism. As part of the research for the I Exist campaign the National Autistic Society Northern Ireland commissioned a leading market research company to survey a sample of 500 people aged 16 and over across six counties in Northern Ireland. We asked our respondents what proportion of the population they thought were affected by autism. The vast majority 90% did not know how common autism was. Our survey revealed that 87% of the population have heard of autism but far fewer only 48% had heard of Asperger syndrome. There was also considerable confusion about the nature of autism for example 62% of our respondents believed that people with autism have special abilities for example in maths or art. Widespread misconceptions make it difficult for people with autism to get the right kind of support.

### **Resources**

The main challenge to the work of RASDN or to the cross departmental strategy as outlined in the Bill is Finance. The historic underfunding of autism services needs to be addressed. The Minister has made resources available for autism which we welcome but more is urgently needed if we are to meet the needs of people with

autism and their families and carers. This is particularly relevant in relation to the development of services for adults with autism. In the present economic climate this will be challenging.

In an analysis of the economic costs of autism in the UK Martin Knapp concluded <sup>2</sup>“If early intervention could successfully change some aspects of behaviour that are cost-raising, both in childhood and subsequently, it may allow cost savings to be made and quality of life improvements to be achieved.

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<sup>2</sup> Martin Knapp, Renée Romeo and Jennifer Beecham (2009) Economic cost of autism in the UK, *Autism* 13: 317-337

<http://www2.lse.ac.uk/ERD/pressAndInformationOffice/newsAndEvents/archives/2009/05/MartinKnappAutism.aspx>