Research and Library Services

Northern Ireland Assembly

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IMPROVING SERVICES FOR PEOPLE WITH AUTISTIC SPECTRUM DISORDER

Research and Library Services

This report, which has been commissioned by the All Party Assembly Group on Autism, provides information on the possible ways that Government could further ameliorate the difficulties faced by those individuals with an Autistic Spectrum Disorder. The report is in three sections. Section one outlines what provision is needed by individuals with Autism. Section two sets out what provision is currently available to assist those with Autism. Section three looks at the ways forward, and how government can make a positive impact on the lives of people with Autism.

Summary of Key Points

1. Autism is a life long condition and an individual with ASD may need support throughout his/her life.

2. The needs of individuals with Autism are wide-ranging but can be best described in two categories; clinical need and associated need.

3. Parents usually voice concerns about their child at around 15 to 18 months. However, although Autism is considered a neurological disability, no specific medical test or procedure can confirm a diagnosis.

4. The types of interventions available range across health and education and include behavioural treatments, education based approaches and non-verbal communication systems.

5. The Bamford Review of Mental Health and Learning Difficulties, in considering the provision of services for those with ASD, pointed out the importance of good systems of training.

6. The ‘I Exist’ campaign highlighted the gap between the support that autistic adults need and what they actually receive. As part of the campaign a survey was carried out to ascertain the adequacy of support for people with ASD. One result was that 47% of parents and carers of autistic adults with a learning disability felt that a lack of understanding of Autism was a barrier to receiving support.

7. The fact that there is no accurate picture of the number of people with ASD is a major issue for service provision.

8. A review of the research evidence suggests that there is a lack of available services for individuals with ASD.

9. There are three main options for government to improve on ASD services. These are:

    a. Government can continue to use the existing policy mechanisms to provide services for people with ASD but apply additional funding with earmarking of resources to the task.

    b. Government can take a strategic look at what they want to achieve in providing ASD services and develop a specific cross cutting strategy to improve on the coordination of the services and to eliminate gaps.

    c. Government can create a legal obligation for action on ASD by enshrining it in legislation.

10. There is no legislation in the United Kingdom or Ireland that is specific to ASD and a possible approach to improving services for individuals with ASD is for governments to pass ASD specific legislation. There are three main options for legislation:

    a. Firstly, information gathering legislation designed to establish information on ASD as in the US Combating Autism Act. This type of legislation ensures that research is being funded and carried out to map ASD, to monitor prevalence, to understand its causes and to highlight best practice in support and treatment.

b. Secondly legislation can be sought to counter discrimination against people with ASD including filling the gaps where existing legislation is believed not to be adequate.

c. The third option is to create legislation which requires government to provide Autism services or which establishes a specific Autism Strategy.

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INTRODUCTION

This report provides information to the All Party Assembly Group on Autism on the possible ways that Government could further ameliorate the difficulties faced by people with Autism. The report is in three sections. Section one outlines what provision is needed by individuals with Autism. Section two sets out what provision is currently available to assist those with Autism. Section three looks at the ways forward, and how government can make a positive impact on the lives of people with Autism.

DEFINITION

A detailed definition of Autism and Autistic Spectrum Disorder (ASD) has been provided in earlier papers and will not be rehearsed at any length here. However a brief definition is as follows:[1]

> *An Autistic Spectrum Disorder is a complex developmental condition that essentially affects the way a person communicates and relates to people. The term "autistic spectrum" is often used as the condition varies from person to person. Asperger's Syndrome is a condition at the more able end of the spectrum. At the less able end of the spectrum is Kanner's Syndrome also sometimes called 'classic autism'.*
>
> *People with autism generally experience three main areas of difficulty, which are commonly referred to as 'the triad of impairments'.*
>
> - *Social interaction (difficulty with relationships, for example appearing aloof and indifferent to other people).*
>
> - *Social communication (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice).*
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> - *Imagination (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued repetitively).*

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[1] Autistic Spectrum Disorder (ASD), Research Paper 73/08, Northern Ireland Assembly (2008), retrieved 18 June 2008. http://assist.assemblyni.gov.uk/services/rsrchlib/research/reports/dept/hssps/2008/foster7308.pdf

SECTION ONE: WHAT HELP DO INDIVIDUALS WITH AN ASD NEED?

Autism is a life long condition and lobby groups argue that anyone with an ASD needs support throughout his/her life. The needs of individuals with Autism are wide-ranging but can be best described in two categories; clinical needs and associated needs.

1. Clinical needs include the direct issues surrounding the Autism condition; diagnosis, therapies, education and health. These clinical needs mainly impact on the services provided by the Department of Health, Social Services and Public Safety (DHSSPS) and the Department of Education (DE).

2. Associated needs would be strategies put in place to alleviate the problems associated with having a condition which impacts negatively on an individual's ability to interact with others or to communicate their needs effectively. These associated needs impact on a wide range of departments, beyond DHSSPS and DE they also impact on Housing, Social Services, and employment among others and therefore impact on the Department of Social Development (DSD), the Department of Culture, Arts and Leisure (DCAL) and the Department of Employment and Learning (DEL).

Clinical needs can be further disaggregated into the categories of; **Diagnosis, Treatment and Training**, while associated needs are often described as **Support**.[2] Each of these four areas will be considered individually.

DIAGNOSIS

Research has pointed to the benefit of diagnosing Autism as early as possible. The National Institute of Child Health and Human Development (NICHD) in the United States has pointed out that:[3]

> *Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. The sooner a child begins to get help, the more opportunity for learning. Because a young child's brain is still forming, early intervention gives children the best start possible and the best chance of developing their full potential.*

In agreement with this point the 2002 Task Group report on Autism, looking at ASD provision in education said:[4]

> *There is a consensus of opinion among professionals and researchers that early intervention, and therefore, early diagnosis, is essential to positive developmental and educational outcomes for the child with ASD.*

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[2] P5 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[3] P7. National Institute of Child Health and Human Development, *Autism Overview: What we Know* (2005).

[4] Pix Report of the Task Group on Autism, *The Education of Children and Young People with Autistic Spectrum Disorders* (2002)

Early diagnosis is therefore vital for early intervention and early interventions have lifelong implications. The importance of early intervention is highlighted by the Hampshire County Council which points out that:[5]

> *The difficulties connected with an autistic spectrum disorder are lifelong. However, it is clear that what parents/carers, teachers and others who work with young children do in the early years has a great impact on the child's future. Early intervention in the areas of social understanding, language and communication are key. When parents/carers and professionals work closely together they produce the best results.*

There is consensus that diagnosis of Autism can take place when a child is between two and three years of age. However the milder forms of ASD may not be picked up until later and conversely some symptoms of classic Autism may be noticed at 8 months.

In reality, diagnosis usually happens later than at two to three years of age. Parents usually voice concerns about their child at around 15 to 18 months.[6] However, although Autism is considered a neurological disability, no specific medical test or procedure can confirm a diagnosis. To gather information to accurately profile an individual's strengths and needs, a variety of tests, assessments, and evaluations need to be administered by trained professionals from a variety of disciplines such as; child psychiatry, paediatrics or psychology. Early diagnosis also helps parents to adjust and accept their child's differences. Gray (2003) found the median age of diagnosis to be nine years.[7]

> *This meant an exceptionally long referral process, involving contacts with a large number of professionals as parents struggled to find an accurate diagnosis of their child's disability. Very often it was mothers who had this responsibility and they perceived the failure of health care workers to make a quick diagnosis had several negative effects. First, they had the difficulty of relating complicated and, initially, sometimes inaccurate information to their husbands. Second, the absence of an accurate diagnosis exposed many mothers to charges of parental incompetence by health care workers, a charge that was often repeated by their husbands and members of their wider family.*

TREATMENT

Once a child has been diagnosed as having ASD it is then the role of professionals to put in place the most appropriate interventions. However, there is no one intervention or treatment for individuals with ASD.[8]

> *It is generally agreed that no single intervention will suit all autistic people, and that any intervention can have negative as well as positive effects.*

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[5] http://www3.hants.gov.uk/childrens-services/specialneeds/sen-home/sen-intro/sen-support-autism.htm.

[6] Ozand et al (2003) cited in Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[7] http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=307&a=3342

[8] P2 Autism, Postnote, No. 302, Parliamentary Office of Science and Technology, Feb 2008.

The types of interventions available range across Health and Education and include behavioural treatments, education based approaches and non-verbal communication systems.[9] Due to the range of interventions available, it can be difficult to ascertain the right one to suit a child's needs. In addition the benefits of a number of interventions have not yet been fully or adequately evaluated.[10]

> *Currently there is no definitive, single treatment for ASDs. However, there are a variety of ways to help minimize the symptoms and maximize learning. Persons with an ASD have the best chance of using all of their individual capabilities and skills if they receive appropriate behavioral and other therapies, education, and medication. In some cases, these treatments can help people with autism function at near-normal levels.*

A brief overview of the range of interventions possible for those with ASD is given here.

Behavioural therapy and other therapeutic options	Behaviour management therapy works to reinforce wanted behaviours and reduce unwanted behaviours. It is often based on Applied Behaviour Analysis (ABA). A variety of different applications of ABA are used for people with autism. A variety of health care providers can also help individuals with ASDs and their families to work through different situations. Speech-language therapy can help people autism improve their general ability to communicate and interact with others. Occupational therapy can help people with autism find ways to adjust tasks and conditions that match their needs and abilities. Physical therapy can create activities and exercises to build motor control and to improve posture and balance. For example, they can help a child who avoids body contact to participate in activities and games with other children.
Education	When a child is diagnosed with ASD, their educational needs are assessed. Some children may need to attend a specialist school, whereas others may be able to attend a mainstream school, but require some extra support during lessons. In some cases, it might be more appropriate for the child to be educated at home. Most schools that educate children with autism have adopted the TEACCH approach (Treatment and Education of Autistic and related Communication handicapped Children). TEACCH is based on the principle that children with autism learn better in a structured educational environment, and each child should have a unique programme based on regular assessment of their abilities.
Communication	Many children with ASD benefit from support with communicating in social situations. This may take the form of social groups, social stories, through behavioural therapies, counselling or speech and language therapy. Some children with ASD may be taught social skills, such as

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[9] P2 Autism, Postnote, No. 302, Parliamentary Office of Science and Technology, Feb 2008.
[10] P8 National Institute of Child Health and Human Development, *Autism Overview: What we Know*, 2005.

	greetings, turn taking in conversation, and watching for cues in social skills groups, which may be run by speech and language therapists or teachers. Children with autism tend to be visual learners and find it easier to understand the world about them using visual aids. The Picture Communication Exchange System (PECS) involves the adult using pictures as symbols in order to teach the child the names of different objects. Gradually, the child is taught to exchange a picture for the object they want, to construct simple sentences using the pictures, and indicate choices between various objects
Medication	Medicines cannot be used to treat ASD. However, medicines can be used to control some of the additional symptoms, such as hyperactivity or obsessive behaviour. However, some medicines that are used to treat the additional symptoms of ASD can cause side effects, so are only used when the benefits outweigh the risks of taking them.

TRAINING

Training covers a number of areas. For instance, central to early diagnosis and effective treatment is the need for adequate training for those professionals that come into contact with children. At its widest point, awareness training is needed to ensure that those who come into contact with individuals with ASD are able to acknowledge the complex needs of individuals with ASD and that social and communication issues are taken into consideration. A more focused perspective on awareness of ASD is that professionals will be trained in order to recognise behaviours associated with ASD to allow for early diagnosis. After diagnosis there are training needs for the child's family or other carers in how best to interact with the child. There is also training needed by those service providers who will come into contact with the individual at what ever age and his/her family. The Welsh Autism Action Plan points out that:[11]

> *Studies suggest that the lives of children and adults with ASD may only improve if society has a better understanding of their condition.*

The Bamford Review of Mental Health and Learning Difficulties, in considering the provision of services to individuals with ASD, also pointed out the importance of good systems of training:[12]

> *Staff delivering services to people with ASD and their families must be adequately trained to ensure they are competent for the task. In addition, families and carers need training to fulfil their role. Better general awareness of ASD among primary care and community staff, especially those dealing with young children, would enhance recognition of problems and facilitate earlier referral for assessment.*

TRAINING FOR PROFESSIONALS

As the definition of Autism has broadened, and the prevalence increased, more and more professionals come into contact with autistic children. In a short number of years ASD has grown from a little known disorder being dealt with by small teams of

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[11] P9 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government.

[12] http://www.rmhldni.gov.uk/autistic_spectrum_disorders.pdf

experts to a condition being experienced in mainstream schools and services. There is a need for professionals in these situations to be aware of the condition and adequately trained in how to deal with it. The list of professionals who could be involved in diagnosing a child with Autism is long. Health Visitors and General Practitioners (GPs) who come into contact with children from an early age must be able to spot the signs and initiate diagnosis as well as doctors in hospitals, teachers, social workers and others who need to be trained in how to approach and care for autistic children. A 2001 report by the Public Health Institute for Scotland (PHIS) identified the training needs associated with ASD.[13]

> *Training and awareness were seen as crucial for various groups working in the ASD field. First, it was essential for those who were in a position to recognise a possible autistic spectrum disorder in the early stages, so that they might be confident in identifying possible signs and referring appropriately. This was important to a wide range of professionals including health visitors, general practitioners, school medical staff, teachers, social workers, nursery staff and the members of community mental health and learning difficulties teams. Early recognition required professionals to have an understanding of this area.*
>
> *Second, training and awareness were seen as being vital for the wide range of professionals, carers and specialists who came into contact with people with ASD, to ensure appropriate practice and to gain the confidence of parents and carers in services.*

Guidelines from the “National Initiative for Autism: Screening and Assessment” called for a national structure of training professionals to understand ASD.[14] They called for; Joint multi-agency programmes of ASD awareness training on a continuous basis for all professionals working with children in the community and for parents/carers, regular ASD specific training for all those providing assessment and diagnosis and training for staff delivering both specific ASD interventions and other interventions for children with ASD. The report cites the West Midlands SEN Regional Partnership, 2001: [15]

> *It is generally accepted that training is the key to the successful placement of children and young people with autistic spectrum disorders (ASDs). An excellent teacher or support assistant with no formal, specialist training may be able to work with a pupil with an ASD but to really understand how that pupil thinks and learns, they will need a sound background knowledge of autism. Teachers and Learning Support Assistants (LSAs) need to know how to develop pupils’ communication, interaction and flexible thinking/behaviour and to also understand why they are working in a particular way with an individual child. In addition, other members of staff (administration, mid-day supervisors and drivers and escorts) need a general level of awareness of ASDs to enable them to respond appropriately to individual pupils.*

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[13] P10 Public Health Institute of Scotland (2001). *Autistic Spectrum Disorders – Needs Assessment Report* (The PHIS Report). Glasgow: PHIS/NHS Scotland.

[14] P53 National Autism Plan for Children (NAPC), *Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders (ASD),* The National Autistic Society 2003 London.

[15] P52 National Autism Plan for Children (NAPC), *Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders (ASD),* The National Autistic Society 2003 London.

TRAINING FOR PARENTS

Having a child diagnosed with ASD is a very difficult time for most parents and carers and requires help and support to help them get through the initial shock and then training to enable them to care for their child and help them reach their potential. Reactions to a diagnosis differ from family to family but as the National Autistic Society website describes, there are some common themes:[16]

> *Parents felt relief to be a benefit of having a diagnosis: they no longer feel that the problems they face are due to their lack of parenting skills and they have an explanation for themselves and others as to why their child exhibits unusual behaviours.*
>
> *Parents may also react by crying; feel surprise, devastation or helplessness; and by wanting additional information about autism. However, it is acknowledged that the information they receive is not enough. The National Initiative for Autism: Screening and Assessment (NIASA) report (2003) stresses the need to provide more information and to involve families throughout the assessment process. For example, local parent groups, education and training for parents, carers and professionals and information about support services are important.*

SUPPORT

The support required by individuals with Autism is substantial and wide ranging. In 2008 the National Autism Society (NAS) launched the ‘I Exist’ campaign to highlight and address the gap between the support that autistic adults need and what they actually receive. As part of the campaign a survey was carried out to ascertain how adequate was support for individuals with ASD. One result was that 47% of parents and carers of autistic adults with a learning disability felt that a lack of understanding of Autism was a barrier to receiving support.

There is no existing government policy that relates specifically to autistic adults. However, in 2006 the Department of Health commissioned a document summarising policies relating to autistic adults to aid social care and health service provision at the local level.[17] There is consensus amongst clinicians, researchers and the voluntary sector that providing for autistic adults should be a priority for future policy. Issues of particular importance are access to appropriate health care, mental health services, social care, adult education, housing, and employment.

ACCESSING SERVICES

The fact that Autism crosses traditional public service boundaries such as health, education and social welfare provides a challenge for local service providers to ensure that individuals don’t fall between service gaps. Where individuals with ASD do access services it is usually via mental health or learning disability teams, but services are less accessible for those that do not have significant additional mental illnesses and/or learning disabilities.

As part of the ‘I exist’ campaign the NAS found that 60% of autistic adults had difficulty receiving services. Government policy recommends the following strategies

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[16] http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=307&a=3342

[17] Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice (2006), Department of Health.

for promoting access to services: pooling resources, joint working protocols, joint training and sharing expertise.[18]

A recent report estimates that of the £25 billion annual cost of Autism to society, 36% can be accounted for by lost employment.[19] In some cases employment may not be appropriate and even among individuals of high intellectual ability, most have difficulty sustaining employment. Without employment individuals are likely to experience less independence and social interaction, suffer from low self-esteem and to claim more benefits. Support including access to information and communication technology can sometimes help autistic adults find employment.

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[18] Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice (2006), Department of Health.

[19] http://www.autismspeaks.org.uk/access_press_autism_cost

SECTION TWO: CURRENT PROVISION, POLICIES AND LEGISLATION THAT GOVERNMENT EMPLOYS TO ASSIST THOSE WITH AUTISM.

In section one, the main types of provision required for those with ASD were discussed. This section looks at how services are actually delivered. Using evidence from various studies it summarises the issues surrounding the provision of ASD services. The research reveals three main criticisms of ASD provision.

1 A Lack of knowledge of the numbers of individuals with ASD
The fact that there is no accurate picture of the number of people with ASD is a major issue for service provision. Due to issues of defining ASD, diagnosis and service delivery mechanisms, there is a dearth of centrally held information. This means that developing services is difficult.

2 A Lack of available services
A review of the research evidence suggests that there is a lack of available services for individuals with ASD.

3 A Lack of coordination for existing services
The fact that service delivery mechanisms are through broader departmental policies means that there is not the "joined up" support that the research evidence says is needed for people with ASD.

THE NUMBER OF PEOPLE WITH ASD

Current UK estimates put the number of people with ASD in the UK at around 540,000.[20] The extensive work carried out in preparation for the Welsh ASD Strategy led them to settle on an estimate of 60 people likely to have ASD in every 10,000 of the population.[21] However these remain only estimates and this alludes to the fact that there are unknown numbers of individuals with ASD.

Diagnosis of ASD is of great importance to policy makers. Research and statistical information point to the increasing prevalence of the condition and this has a major impact on services. The explanation of this increase has been debated at length:[22]

> *Studies investigating this phenomenon have concluded that several factors account for the increase—for example, changing conceptualisation to a spectrum rather than a core categorical condition; changes in diagnostic methods; and the inclusion of children with disorders such as attention deficit hyperactivity disorder, Tourette's syndrome, or tuberous sclerosis as also having autistic spectrum disorder. The prevalence of the broad spectrum of disorders of autism (determined with current diagnostic tools) is agreed to be approximately five to six per 1000 in younger children.*

The main discussion surrounds whether or not the prevalence of ASD is on the increase or that awareness of the disorder means more people are being diagnosed. Many experts believe that the unsociable behaviour, now associated with ASD was

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[20] P14 Knapp et al *The Economic consequences of autism in the UK*, Foundation for People with Learning Difficulties, 2007.

[21] P8 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government.

[22] Gillian Baird, Hilary Cass, Vicky Slonims, *Diagnosis of autism* BMJ (2003) 327:488-493 http://www.bmj.com/cgi/content/full/327/7413/488

as common 30 and 40 years ago but faced a different diagnosis. One commentator points out that:[23]

> *For decades, the diagnosis was given only to kids with severe language and social impairments and unusual, repetitious behaviours.*

A study looking at the increase in prevalence of ASD pointed out that if individuals with previously unspecified disorders are now being diagnosed with ASD then there should be evidence of this in the statistics. The United States of America's Department of Education data shows that the number of students with Autism has risen from 42,500 in 1997 to 225,000 in 2006. At the same time the number of students labelled as having mental retardation has fallen from 603,000 to 523,000.[24]

However some experts say that there are some confounding factors and that something else is happening. For instance Dr Gary Goldstein, scientific adviser to the American advocacy group, "Autism Speaks" believes that the reason for the increased prevalence is complex but that it surpasses the role played by broader diagnosis or genetics.

In truth there is no conclusive answer to why Autism is increasing and given that the definition has changed, year-on-year figures cannot be relied upon. However if the current definition remains as it is then there may be an answer to this question in the future. To this end the issue of diagnosis takes on even more importance.

DATA COLLECTION

From a service delivery perspective the issues surrounding diagnosis are compounded by the fact that data on the numbers of ASD individuals are not held centrally. The first act of the Strategic Action Plan for Wales is to use better systems of data collection to inform the planning and provision of services and in Scotland too it is acknowledged that a good information base is necessary for good service provision.[25]

> *Commissioners need good quality, shared information about current and future demand for support across the wide range of abilities in the autism spectrum. Following the national audit of services for people with autism spectrum disorder in 2003, localities should have robust systems for the collection and dissemination of information about the needs of people with autism spectrum disorder.*

As the basis for an Autism Strategy, the Scottish Care Services Minister has recently announced £500,000 for research into the numbers of adults with Autism. The Minister has said:[26]

> *This study will inform the development of a national strategy designed to ensure that adults with Autism and Asperger's syndrome are supported to have full lives.*

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[23] Mike Stobbe, *Autism "epidemic" may be all in the label*, The Associated Press, November 2007.

[24] http://www.msnbc.msn.com/id/21600784/print/1/displaymode/1098/

[25] P4 *Commissioning Services for People on the Autism Spectrum*, The Scottish Government, Edinburgh 2008

[26] http://nds.coi.gov.uk/Content/Detail.asp?ReleaseID=366876&NewsAreaID=2

In Northern Ireland, because services are provided through a number of policies under different departments a full and accurate picture of the need for support is difficult to achieve. For instance, under the auspices of Special Educational Need, the Department of Education gathers information as part of its School Census. The School Census in 2002 put the number of pupils with ASD at 1073 and in 2006 this had risen to 2740.[27] However this is not the full picture, these are only those children receiving special educational provision at key stages 3 to 5. The situation in Health is that there are no centralised figures of those diagnosed with ASD or receiving interventions.

The 2002 Department of Education Task Group on Autism[28] identified the difficulty of providing figures for people with ASD.

> *Two questions arise: is there a genuine increase in the numbers of individuals presenting themselves with the condition or is there another explanation? And where, on the autistic spectrum, are the numbers increasing? It is difficult to give definite answers, as health, social and educational services do not usually define those with ASD as a distinct grouping. Additionally****, those with an ASD can be considered by different government departments according to their age, ability and home area, making it difficult for any one department or professional to have access to information on the total population with autism.*** *It is also notable that diagnostic tools vary across the various professionals.*

Further to this, a 2007 Department of Education evaluation of early intervention for Children with ASD illustrated the confusion over trying to create an accurate picture of numbers. [29]

> *Each agency was asked if they maintained a database of all children with a confirmed diagnosis of ASD. Four of the five ELBs and eight of the 11 Trusts stated that they did. In the main this contained information about the child; date of birth and date of diagnosis. All ELBs but not all Trusts recorded who made the diagnosis and postcode of the child's home. Information on associated learning disabilities, services received and services required was less commonly held. Other information recorded by a few agencies were the referring agency and if a statement of SEN had been issued. Only two of the HSS Trusts and one of the ELBs stated that the dataset was shared with other agencies (in this instance the information came from HSS Trust to the ELB).*

This lack of centrally held and shared information makes it difficult to develop an overview of what services are needed. In the wake of his chairmanship of the Independent Review of Autism Services, tasked with recommendations on how to improve services, the Review's chair, Lord Maginnis, noted to the Health Committee that:[30]

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[27] http://www.deni.gov.uk/index/32-statisticsandresearch_pg/32-statistics_and_research_statistics_on_education_pg.htm

[28] P16 *The Education of Children and Young People with Autistic Spectrum Disorders: Report of the Task Group on Autism*, DENI, 2002.

[29] P31 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[30] 3 July 2008, Official Report, Committee for Health, Social Services and Public Safety.

> *One of the main disadvantages was that no tangible evidence was being kept. There were no records – nothing that could travel on with the person who was the autistic spectrum. That was a matter of concern to us.*

The importance of a robust “baseline” of information has been noted in the Welsh ASD Strategy and, as the strategy points out, is already being acted upon.[31]

> *The Welsh Assembly Government has already begun to make improvements in data collection across the statutory services for children in Wales.*
>
> *The Development of local services for people with ASD and related disorders should therefore be better informed. Commissioners will need to ensure that they share information to jointly plan and meet the needs of children, young people and adults with ASD.*
>
> *It is acknowledged that further specialist research is needed in this area if we are to improve our knowledge and the evidence base to inform the future planning and development of services for people with ASD.*

This overview of the evidence on the impact of the lack of baseline information illustrates the problems that are posed for making improvements in services. The current situation is that if a need is identified then it is the relevant department’s duty to react within its existing priorities. With Autism, the fact that it is a life long condition means that future services need to be planned.

THE AVAILABILITY OF SERVICES

The recent increase in the numbers of people diagnosed with ASD has been likened to an “autistic spectrum wave”.[32] The rise in numbers of diagnosed pupils from 2002 to 2006[33] is evidence of this wave. This increase has given services little time to adjust to meet the related needs of these individuals. Therefore it is unsurprising that the various reports and reviews outline the stresses on what services are available.

A 2007 report by the Westminster All-Party Parliamentary Group on Autism summarises the findings of studies into the impact of policy on families of autistic individuals:[34]

> *These studies found poor outcomes and a shortfall of services for people with autism and their families:*
>
> - *Only 30% of parents were satisfied with autism understanding of all staff in the school.*
> - *66% of parents believed their choice was constrained by a lack of provision.*
> - *70% of parents saw lack of care facilities as a barrier to work.*

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[31] P8 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government.

[32] P iii *Report of the Task Group on Autism, The Education of Children and Young People with Autistic Spectrum Disorders* (2002)

[33] http://www.deni.gov.uk/index/32-statisticsandresearch_pg/32-statistics_and_research_statistics_on_education_pg.htm

[34] P5 *Policy into Practice*, All Party Parliamentary Group on Autism, July 2007

- *Only 15% of carers received any support from social services in their caring role.*

In Northern Ireland there have been a number of reports and reviews looking at Autism services both from a health perspective and from an education perspective. The Task Group on Autism was established in November 2000 to make recommendations on educational provision for children and young people with Autism. Although it concentrated on educational provision it also made comments about health provision and social care. The report concluded that: [35]

> *The Task Group has found that within the last few years educational, health and social services provision for children and young people with Autistic Spectrum Disorders (ASD) has entered a period of rapid improvement in many areas of Northern Ireland. However, parents, voluntary bodies and statutory bodies alike recognise that there is still much progress to be made before it will be possible to say that all children and young people with ASD are being identified and that their needs are being fully met. There is, in particular, a demand for more prompt access to diagnostic services at an early age and that these services should be followed immediately by effective home- and school-based intervention. There is also considerable concern about provision for children with ASD and challenging behaviour.*
>
> *The report highlights the fact that there is an "autistic spectrum wave" rising through the school system, and that as it progresses there will be a large increase in the numbers of pupils, students and trainees with a diagnosis of ASD and a large increase in demand for appropriate services and educational provision.*

In 2003 there was criticism of Autism services by the Coroner for Greater Belfast following an inquest into the death of a 43-year-old east Belfast woman. The woman died after suffering head injuries, multiple broken ribs and a punctured lung, which the pathologist said were consistent with someone jumping up and down on her. The coroner's conclusion was that the woman had fallen asleep in bed with her 12-year-old autistic son. The boy was questioned by the police about his mother's death, but the Director of Public Prosecutions decided no further action should be taken. In a newspaper article[36] the Coroner described Autism Services as inadequate.

The recent report of the Independent Review of Autism Services (2008) stated:[37]

> *The Review Team recognises the lack of ASD services across N. Ireland, particularly services for older adolescents and adults. Therefore, the need to develop specialist ASD services forms the main focus of the Review report, together with the need to create more co-ordination and cohesion across the broad range of services provided.*

This overview of the evidence points to the "inadequate" nature of services for people with ASD and illustrates the fact that Autism is a life long condition with potentially extreme and even fatal consequences of a lack of support. Lastly it points to a lack

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[35] Pii Report of the Task Group on Autism, The Education of Children and Young People with Autistic Spectrum Disorders (2002).

[36] *Coroner criticises autism services*, Wednesday, BBC News Online, 15 January, 2003 http://news.bbc.co.uk/1/hi/northern_ireland/2662063.stm

[37] P6 Independent Review of Autism Services, May 2008.

of coordination between service providers in meeting the needs of people with Autism.

COORDINATION OF SERVICES

In Northern Ireland, the common theme from the various reports and reviews is that there is a need for a coordinated approach for Autism services. The recent review of Autism Services found that there was "a lack of cohesion and continuity in the delivery of services."[38]

A major criticism of current delivery is that it is compartmentalised into departmental remits and then again into the work of individual Boards and Trusts. Because Education reacts specifically on Education matters and Health on Health matters and also because each Education Eoard and each Health Trust manage the provision in their own areas there is little coordination in services. There are variations in delivery across the trusts and boards in actions that have been taken. The evaluation of ASD support for children by the Department of Education for Northern Ireland[39] identified that there is no consistent approach nor joined up strategic policy.

> *Other than the Report of the Task Group on Autism which emanated from DofE, there appear to be few comprehensive statements of policy in regard to children with ASD and their families. This means that service developments are dependent on committed professionals and parents who have to act with few extra resources at their disposal.*

Interventions put in place in Northern Ireland have been at the local level which the DE evaluation points out are "to the obvious disadvantage of families in areas with less well-developed services."[40] In the recent Independent Review of Autism Services the Review Team recognised "the lack of ASD services across Northern Ireland" [41] and that:

> *the need to develop specialist ASD services forms the main focus of the Review report, together with the need to create more co-ordination and cohesion across the broad range of services provided.*

Given that the Boards and Trusts work independently from one another the services offered and the expertise available in each board and trust can vary considerably. This lack of consistency can be seen in diagnostic services through to support services.[42] In July 2008 the Northern Ireland Commissioner for Children and Young People called for an end to the "postcode lottery" that was "leaving some children with suspected autism awaiting for up to nine years for assessment and treatment. "[43]

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[38] NI Official Report, Committee for Health and Social Services and Public Safety, 3 July 2008.

[39] P9 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[40] P41 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[41] P 6. Independent Review of Autism Services, May 2008.

[42] Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007)

[43] Fears over delays in autism diagnosis, July 2008, Newsletter

With the exception of the Strategy for Wales, ASD does not have a specified policy in the UK; instead it is dealt with through the more general policies supporting those with social, mental and disability problems. That is, if an individual with ASD is seen to have specific needs then he or she should receive help. Both the Department of Health and the Department of Education specify provision for individuals with ASD under their broader policies while other departments do not mention Autism but will make provision for those individuals that do have a wider diagnosis of disability.

In its publication "Better Services for People with an Autistic Spectrum Disorder" (2006), the Department of Health in England acknowledges that there is a problem in delivering services to people with ASD and their families and carers.[44]

> *The current position whereby some people with an ASD "fall through" local services – in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy.*

However instead of suggesting a bespoke ASD strategy that brings the relevant services together the publication details how the existing policies should impact on those with ASD.[45]

> ***It does not develop new policy** but explains what existing policies mean for local commissioners and providers in terms of government expectations for the delivery of public services for people with an ASD.*
>
> *This document does not try to make a special case for people with an ASD but aims to redress poor general understanding of the condition, clarify how national policy applies and to make clear what services people with an ASD can expect to have access to, regardless of how services are configured in their local area.*

The 2006 publication focuses on adults with ASD (16 years +) and lists the six most relevant strategies and policies:[46]

Policy	**Description**
Local Authority Circular LAC (2002)13: Fair access to care services: guidance on eligibility criteria for adult social care 2002	"Fair access to care" (FAC) sets out how social services should identify which people are eligible for social care. It provides a Framework designed to create a more consistent approach to determining eligibility across England.
Valuing People: A New Strategy for Learning Disability for the 21st Century. 2001	The Valuing People White Paper focuses on achieving full lives for people with learning disabilities. It aims to stop the inequalities in how people with learning disabilities live their lives. It lists things not working in the current system like; support for carers, services for young people becoming adults, the lack of choice and control experienced by many people, unmet health needs, limited housing choice, institutionalised group day

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[44] P7 Department of Health, *Better Services for People with an Autistic Spectrum Disorder*, 2006.

[45] P4 Department of Health, *Better Services for People with an Autistic Spectrum Disorder*, 2006.

[46] P4 Department of Health, *Better Services for People with an Autistic Spectrum Disorder*, 2006.

	opportunities, the fact so few people have jobs; the needs of people from minority ethnic communities being overlooked; inconsistency in services and poor partnership working. It commits to tackling these things.
The National Service Framework for Mental Health, 1999 and the National Service Framework for Mental Health – Five Years On, 2004	The National Service Framework for Mental Health sets out seven national standards. It lays out an expectation that most mental health needs will be tackled locally, by general practice and primary care supported where necessary by local and other specialist mental health services. The framework says that health and social care organisations should work in partnership.
Our Health, Our Care, Our Say: A New Direction for Community Services (2006)	The vision set out in Our Health, Our Care, Our Say is to make services more responsive, focus on people with complex needs and shift care & supports closer to home. It seeks to give people choice and control over their life and the health and social care services they get.
Improving the Life Chances of Disabled People 2005	Improving the Life Chances of Disabled People outlines a twenty year strategy focused to markedly improve the life chances of disabled people in Britain. It focuses on four key areas and gives commitment to supporting delivery. Most notable is the setting up of the Office for Disability Issues based within the Department for Work Pensions which reports directly to the Minister for Disabled People.
National Service Framework for Long Term (Neurological) Conditions 2005	The NSF for long term neurological conditions sets out quality requirements and evidence base for services for people with long term neurological conditions resulting from disease of, injury or damage to the body’s nervous system. It applies to health and social care services working alongside other key agencies such as providers of transport, housing, employment, education, benefits and pensions. Individual neurological conditions are not separately addressed in the NSF. It states “that although the NSF focuses on improving services for people with neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition. Commissioners are therefore encouraged to use this NSF in planning service developments for people with other long-term conditions”.

The same approach is taken in relation to children with ASD; they too receive support from wider policies such as the Special Educational Needs (SEN) Action Programme and the[47] Children’s National Service Framework (NSF).[48]

> *National service frameworks are policy documents that set standards of care for the Government’s priority areas for the NHS in England. The Children’s NSF, produced in 2004, sets 11 standards relating to all*

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[47] The term 'special educational needs' has a legal definition. Children with special educational needs all have learning difficulties or disabilities that make it harder for them to learn or access education than most children of the same age. These children may need extra or different help from that given to other children of the same age.

[48] The Children's NSF, published on 15 September 2004, sets standards for children's health and social services, and the interface of those services with education.

> *children, particular groups of children, and maternity services. Unlike other such frameworks, the Children's NSF is aimed at an age group rather than a condition and does not set specific local targets. Rather, the whole document is expected to be implemented by 2014, with immediate priorities determined locally.*

The Department of Health went on to publish a supplemental chapter to the framework, signposting an autistic child's journey through social services as an example of best practice. A survey by the Westminster All-Party Parliamentary Group on Autism (APPGA) found that few local authorities were using the Autism chapter but among the minority who were, it was used to establish Autism-specific provision.

These documents point to the efforts being made in Health to show how its existing policies should impact on people with ASD. However these too are only part of the picture in that they are specific to Health.

In Education the driver for services to children with ASD is the policy of Special Educational Need (SEN). The Education Act 1996 (Education (Northern Ireland) Order) legally defines children with SEN as children who have a considerably greater difficulty in learning than others the same age. It also includes children who cannot use the educational facilities which other children of a similar age use, because of their disability. Children under school age, who would fall into either category without extra help, are also included. These children may need extra or different help in education from that given to others without SEN. The Special Educational Needs and Disability (Northern Ireland) Order 2005 strengthened the rights of children with Special Educational Needs across the whole education sector. In addition, a review of SEN is getting underway which may impact on the interventions available for children with ASD.

The research suggests that the problem with this approach is that individuals with Autism can fall through the gaps in services if there is no policy specific to them and if services are not coordinated to meet their needs. For instance the 2007 report by the Westminster All-Party Parliamentary Group on Autism found that:

> *At present, the NSF is not seen as a 'mustdo' document and, as such, is overshadowed by other, more urgent priorities. Its progress is limited by funding, staff and structural difficulties.*

In Northern Ireland the Department of Education's 2007 evaluation of Autism services for 2 – 4 year olds also found that there was no consistent approach across the Education and Library Boards (ELBs):[49]

- *There is an absence of ASD Policy Documents, in preference for "generic" special educational needs policies in WELB and SELB.*
- *The limiting of ASD Policy Documents to ASD specific services in SEELB and BELB i.e. not reflected in "Board Policy Documents".*

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[49] P8 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

- *Although ASD is referenced in some Board Policy Documents, there is an absence of an ASD policy underpinning specific services.*

The report's authors voiced surprise at their findings given the recommendations of the Task Group report in 2002. The report concluded that:

> *Other than the Report of the Task Group on Autism which emanated from DofE, there appear to be few comprehensive statements of policy in regard to children with ASD and their families.*[50]

As well as the issues across the Education and Library Boards, the report found that there was a "marked variation across Boards and Trusts".[51]

Conversely, the recent Independent Review of Autism focused on services provided by the Department of Health and Social Services but acknowledged the crossover between Health and Education in delivering ASD services. The review pointed to the need to pool resources to best meet need. The Review recommended that extra investment as well as better coordination between services would provide a more efficient infrastructure of service to meet need on a regional level rather than unequal provision across local areas.

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[50] P9 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

[51] P41 Roy McConkey, Greg Kelly and Arlene Cassidy, *An Evaluation of the need and early support for children (aged 2-4 years) with and Autistic Spectrum Disorder in Northern Ireland* (2007).

SECTION THREE: THE WAY FORWARD

The previous two sections have detailed a number of points. Firstly that, irrespective of the reason, ASD is increasing in prevalence. This has had a number of knock on effects; creating pressures on available services. It has meant that local and regional service delivery, especially in education and health, have been using already limited finances to meet the additional need. Although ASD has found its way into the language of more mainstream policies such as SEN and Learning Disabilities it is in competition for resources under these policies. As the evidence cited in section two illustrates this has lead to the current situation in which there are no centrally held figures upon which to base service provision; the increasing prevalence of people with ASD has lead to stresses on existing services and that the services that are available are delivered unevenly and without central coordination.

Section two detailed the current situation regarding services for those with ASD and in doing so highlighted the consensus that there is room for improvement. This chapter examines the possible measures that government can take to improve on the current situation.

Potential area for improvement of ASD services can be explained in three main categories of response to the criticisms levelled at ASD provision.

1. Government can continue to use the existing policy mechanisms to provide services for individuals with ASD but apply additional funding and earmarking resources to the task.

2. Government can take a strategic look at what they want to achieve in providing ASD services and develop a specific cross cutting strategy to improve on the coordination of the services and to eliminate gaps.

3. Government can create a legal obligation for action on ASD by enshrining it in legislation.

This section examines each of these in turn.

IMPROVING ON EXISTING MECHANISMS

The most common way of improving services to people with ASD is through policies and mechanisms already in place such as Special Educational Needs and Learning Difficulties. The reasons for this are firstly that it is immediate, that there is no time needed to set up new services and structures. Secondly, governments are only now getting to grips with what the increase in prevalence of ASD means for service delivery and have not yet been convinced of the argument for making ASD a special case.

Government has a culture of working in departmental silos that have a vertical structure within which coordination, policy and funding flow from the top down. Within these constraints the quickest way for government to improve its services for people with ASD is to provide additional resources within these constraints. That is, to provide extra funding to existing stuctures or provide direction or priorities in relation to ASD. This is the approach taken in Northern Ireland and in England and Scotland. ASD needs are met through mainstream provision meaning that when additional need is identified, resources should be made available to meet that need either through specific planning, extra funding or changes in priorities. The criticism leveled against this approach is that it can be accused of not being strategic and proactive but rather as piecemeal and reactive.

The positive aspect of this less strategic approach to improving services for people with ASD is that improvements can be made quickly. For instance the Independent Review of Autism Services' recommendations for Northern Ireland fall short of being a strategic plan but rather offer a way to better utilise what services are available and how they can be improved and increased to more quickley meet need.[52]

> *This makes it essential that we form a clear picture of how we can set out those needs in order of priority, plus a realistic, pragmatic approach to what we can hope to put in place by 2013.*

The approach taken by Scotland and England has been to identify the existing policies that can meet the needs of people with ASD. As noted earlier, in England a number of documents have been produced to identify the policies relevant to people with ASD and how they should impact positively on the lives of children and adults with ASD. So too in Scotland the recently published "Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance"[53] details how those commissioning health and social care services should be cognisant of the needs of ASD individuals:[54]

> *There are a number of legislative and policy requirements which either have a specific focus or are applicable to people with autism spectrum disorder. Action to meet these existing requirements should mean that local authorities identify people with autism spectrum disorder who require support, and provide appropriate services.*

The Independent Review of Autism Services has put forward its recommendations for how the needs of people with Autism should be met. The review team admit that they have essentially produced a health solution and while acknowledging the need for a cross departmental approach, recommend a number of specific measures that could improve provision within Health. The review identified that:[55]

> *While mainly based on statutory HSC services, the Network should also welcome input from other key stakeholders, i.e., Education and Library Boards, families, carers, Voluntary and Community and private sector groups and other statutory partners including the Northern Ireland Housing Executive.*

In response to the review the Minister for Health has stated that:[56]

> *There is a need to address the shortfall in existing ASD services, in areas such as workforce, specialist assessment, early intervention, structured behavioural interventions and family support. I will ensure that these will be delivered through the ASD Action Plan.*

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[52] P6 *Independent Review of Autism Services*, May 2008.

[53] P3 *Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance*, Scottish Government, 2008.

[54] P3 Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance, Scottish Government, 2008.

[55] P 22 Independent Review of Autism Services, May 2008.

[56] http://www.northernireland.gov.uk/news/news-dhssps/news-dhssps-260608-minister-fast-tracks.htm

In addition to the Independent Review for the Department of Health, a new review of Special Educational Need provision by the Department of Education may provide some further initiatives and strategic thinking to further support the needs of children an young people with ASD through the SEN policy.

This departmental approach does not mean that there cannot be creative approaches or cross departmental working, in fact it can be the catalyst for models of good practice. With the advent of the Review of Public Administration (RPA) and the proposals for Area Based and Community Planning at local levels as well as the local commissioning of Health and Social Care, there are opportunities to develop coordinated approaches to problems such as ASD. The approach taken in Scotland and England is to provide guidance at a local level for how local commissioning of services can better meet needs. In light of this some local strategies have been developed which include elements of joined up thinking but under existing policies. For example the Liverpool Aspergers Team has been pointed to as a model of good practice. [57]

> *Autistic individuals that have average and above intellectual ability (for example Aperger syndrome or high functioning autism) are particularly at risk of falling through service gaps. In response to this the Liverpool Asperger Team was set up in 2002, funded by Liverpool Primary Care Trusts and Liverpool City Council. The multidisciplinary team provides co-ordinated services such as assessment, diagnosis and intervention along with specialist knowledge, information and advice. The Liverpool Asperger Team is often cited as an example of good practice.*

In addition the Scottish government has recently published “The Autism Toolbox”.[58] The Toolbox is a resource for schools and local authorities and brings together research and best practice to offer guidance on how schools can best provide for children and young people with ASD. There are also many programmes and projects ran by the voluntary sector which can if funded meet the gaps left by current provision. For instance:[59]

> *The NAS runs Prospects, an employment scheme for autistic clients, which is partly funded by the Department for Work and Pensions. An independent evaluation of the scheme showed that over an eight year period Prospects found employment for approximately 68% of their clients. Further, although finding jobs for individuals was relatively costly, this cost was largely offset by a reduction in benefit claims, and gains in tax and National Insurance. Despite the success of Prospects, there are few schemes of this kind. Further schemes would enable a greater number of individuals to work rather than receive income-related benefits.*

Between health and education, services for people with ASD can be developed and improved and there are examples of good practice. The review of SEN and the Autism Action plan promised by Health as a result of the Independent Review may use best practice to better support the needs of individuals with ASD. However as can be seen from the APPGA survey, without overarching coordination and when competing with other priorities ASD can lose out. The requirements of DE and the DHSSPS are clear enough to see but the same can not be said for the support need for people with ASD in finding a job or claim benefits, or in looking for

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[57] P4 Autism, Postnote, No. 302, Parliamentary Office of Science and Technology, Feb 2008.

[58] http://www.ltscotland.org.uk/Images/AutismToolbox_tcm4-477050.pdf

[59] P4 Autism, Postnote, No. 302, Parliamentary Office of Science and Technology, Feb 2008.

accommodation or looking for social outlets. The fact that an individual can leave school and cease to be supported or can receive support for health needs but not training in social interaction means that the current systems are not meeting needs. It is because of this that the case for a more strategic approach or legislation has been put forward.

CROSS-DEPARTMENTAL AUTISM STRATEGY

The lack of consistency across Northern Ireland and the siloed nature of provision have led to calls for a more strategic approach to be taken to meeting the needs of people with Autism. These calls have been consistent over the last number of years and evidenced in the various reviews and reports discussed above. The main argument used for establishing a strategy is to help coordinate support and to drive services to produce desired impacts. However there is also a financial incentive for developing a strategy as a lack of coordination often leads to duplication and wasted effort, whereas a coordinated strategy ensures efficiency and universal coverage.

A definition of a strategy is a long-term plan for achieving a stated goal. The development of a strategy also produces specific, measurable objectives. The Welsh Strategic Action Plan has been held up as an example of best practice for tackling the issue of Autism. Wales has been heralded as being "the first country in the world to have established a cross-cutting national strategic action plan for ASD".[60]

The approach taken in Wales has been to create an action plan to "drive improvements across both children, young people's and adult services in health, social services and education services - and also expand into areas of housing, leisure and society in general." [61] The driver in Wales was to create a system which meets the needs of individuals with ASD and their families. The purpose of the action plan is to:[62]

> *Set a clear direction of travel for the development of services in Wales by ensuring that specific and measurable actions are undertaken and, on the basis of evidence of prevalence and need, commissioning inter agency services at local, regional or national levels as appropriate.*

The benefit of a government led strategy such as this is that it is cross departmental. It concentrates minds on the end goal of the strategy and different departments then coordinate their services to best reach this goal. The Welsh model has at its centre an implementation manager with the role of coordinating government actions during the initial year of the strategy and identifies "champions" within departments to ensure the implementation of the strategy. This provides a central coordination and a reminder to government departments of their responsibilities under the strategy and where they can feed into the actions of other departments.[63]

> *As appropriate, the responsible authorities should explore the options for joint commissioning approaches.*

The Welsh strategy takes a holistic view and encompasses the services offered across government and importantly, includes the voluntary sector; given that the

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[60] http://www.wales.nhs.uk/newsitem.cfm?contentid=9652

[61] http://new.wales.gov.uk/topics/health/news/22-04-08-autism/?lang=en#main .

[62] P1 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government.

[63] P22 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government.

voluntary sector is an important provider of services. As well as including the education and health needs the strategy also includes the financial and social needs:[64]

> *People with ASD, as all others, require access to a wide range of community based facilities and services that are provided for from premises that are situated along the high streets of Wales. Yet many of these services are not orientated to be able to respond well to the needs of people with ASD.*

Importantly, the Welsh strategy is in addition to and complementary to existing policies, strategies and legislation. Its coordinating remit is to ensure that people with ASD benefit from these existing policies. In ensuring that the strategy is developed around the needs of individuals with ASD rather than on the services, the strategy maps out "pathways" which are to direct individuals through the services and ensure they get the support they need at all stages of their lives.

The Welsh model differs from that recommended by Northern Ireland's Independent Review and what is currently in place in England and Scotland by the fact that Wales has stood back from departmental structures and looked at the provision needed for individuals with ASD as a whole. The uniqueness of the Welsh Strategy is that it is a coordinated approach to the issue. At its core is an acceptance by government that people with ASD are not being properly provided for and it makes a commitment to improve on this. In doing so its action plan joins up services, provides central direction and commitment and looks at a system that is based on individuals being assessed and being provided with the services that they require, irrespective of which department these services are in. Furthermore it raises awareness of ASD and aims to ensure that all services are more open to ASD individuals.

In the House of Lords, the chair of the Independent Review of Autism Services argued for government to consider a National Autism Strategy Lord Maginnis pointed out that:[65]

> *We must get away from an approach that labels children and laboriously moves them from what I call one silo to the next.*
>
> *That is why I want to ask the Government to rethink the provision and planning of autism services and to work to establish and accommodate within a national strategy the best of what is happening in England, in Wales, in Scotland and in Northern Ireland.*

The approach of Scotland and England of providing guidance on how government departments and those commissioning services should utilise existing policy and legislation to meet ASD is also contained in the Welsh Strategy however they do not provide the coordinated cross-departmental direction and commitment. Providing an overarching cross-departmental strategy means gaining the consent of the departments in question. This can be complex and time consuming given that each department will be judged on how it delivers its part of the strategy and that it will entail targeting resources to the strategy to meet its specific indicators. This approach needs substantial political will and it provides an even greater challenge to a coalition government such as in Northern Ireland. The advantage of providing for

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[64] P47 *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*, Welsh Assembly Government .

[65] http://www.publications.parliament.uk/pa/ld200708/ldhansrd/text/80319-0012.htm.

people with ASD through a Departmental action plan such as the one that the DHSSPS has promised to provide is that it does not rely on cooperation with other departments.

Creating a strategy may take time to develop which may not be available when the call is for immediate action. To this end the counter arguments for a strategy are to either provide services through the departmental routes discussed above or to create a requirement on departments to act through the enactment of legislation.

AUTISM LEGISLATION

There is no legislation in the United Kingdom or Ireland that is specific to ASD and a possible approach to improving services for individuals with ASD is for governments to pass ASD specific legislation. This is an approach which is supported by the ASD sector.

The position of Autism NI and other organisations providing support for people with ASD is that legislation brings with it an imperative for action. Autism NI has coordinated its activity with Autism Cymru, the Scottish Society for Autism and the Irish Society for Autism and formed the Celtic Nations Autism Partnership (CNAP). CNAP has produced its case for ASD legislation pointing out that legislation is about "what **will** be done" rather than a strategy which is about "what **should** be done". [66]

CNAP's argument for bringing about change by legislation rather than by a strategy is that strategies face periodic reviews which may erode the initial focus of the strategy. The argument is that existing legislation which is meant to incorporate ASD does not fit; that disability legislation is skewed toward physical disability and that ASD children can fall through gaps in services. CNAP argues that legislation is needed to cut across the existing services and legislation to create both the impetus and the coordination for an ASD specific service that goes beyond the departments of Health and Education and puts requirements on all public bodies.

The call for ASD legislation comes also from elected representatives. For instance in May 2008 Angela Browning MP progressed the *Adults with Autism* Private Members Bill to:[67]

> *impose duties upon the Secretary of State and certain organisations involved in health and social care in respect of support for people aged 18 and over with autism; and for connected purposes*

Ms Browning, in the first reading of the Bill, points out what is needed:[68]

> *More than three quarters of primary care trusts do not keep a record of how many adults with autism there are in their areas and 86 per cent. of local authorities say that if they had more information about the number of adults with autism in their areas, it would help them with their long-term planning.*
>
> *The Government now intend to support a study of the number of adults with autism. That is why I am not calling for that today, but it is important that action for adults does not wait for that study to report and that that*

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[66] *The Case for ASD legislation* CNAP fact sheet http://www.autismni.org/lobby/The%20Case%20for%20ASD%20Legislation.pdf

[67] http://services.parliament.uk/bills/2007-08/adultswithautism.html

[68] http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm080520/debtext/80520-0004.htm#08052039000002

> *research is reinforced by action locally. Therefore, the Bill would also require local authorities and NHS bodies to identify people with autism in their areas and maintain a register of the numbers, which should also include carers.*
>
> *In addition, the Bill proposes placing additional duties on local authorities and NHS bodies, because despite recent Government guidance to tackle the inaction by local services it is apparent that not nearly enough is being done to support people.*

Also in Westminster a Bill for children with Autism had its first reading. The *Education (Children with Autism) Bill* was introduced to parliament in January 2008 by Lee Scott MP to:[69]

> *make provision about the education and training of children with autism and Asperger's syndrome;*

The scope for legislation is broad and Autism legislation can be specific or wide-ranging. For instance the United States of America's legislation, the *Combating Autism Act* 2006, is designed to enhance research, surveillance, and education regarding Autism Spectrum Disorder. In particular it: [70]

> *Authorizes Research Under NIH To Address The Entire Scope Of Autism Spectrum Disorder (ASD).*
>
> *Authorizes Regional Centers Of Excellence For Autism Spectrum Disorder Research And Epidemiology.*
>
> *Authorizes Activities To Increase Public Awareness Of Autism.*

The 2006 Act is very focused on the research base; on information gathering and the awareness raising aspect of developing ASD services. It calls on the Interagency Autism Coordinating Committee (IACC) to enhance information sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about Autism activities, programs, policies, and research among the Federal government, several non-profit groups, and the public.

A further two bills have been seeking support in the US Senate and House of Representatives but as of yet have not been successful. The "*Empowering Children with Autism through Education Act*" is again about the gathering and dissemination of information on best practice on strategies and how best to improve services. However the "*Expanding the Promise for Individuals with Autism Act*" would, if brought into law, require the Secretary of Health and Human Services to establish Autism services and award grants to States for accessing Autism services.

The main argument against legislation is that it is making ASD a special case; that it makes services available based on diagnosis rather than need. This argument contends that a case could emerge where an individual with no diagnosis but with defined needs does not receive services as readily as someone with a diagnosis of

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[69] http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm080116/debtext/80116-0004.htm#080116103000004

[70] http://assist.assemblyni.gov.uk/services/rsrchlib/research/reports/dept/hssps/2008/foster7308.pdf

ASD but with less obvious needs. In addition giving ASD specific legislation may mean that lobby groups for other disorders would campaign for specific legislation for their causes. In addition, the argument could be made that to make a special case of Autism is discriminatory against other groups and so open to challenge.

One of the main arguments in favour of legislation is that due to the unique nature of ASD, bringing a case is difficult and many cases are settled before going to court. The current legislative route for a person with ASD not receiving appropriate care is through Equality, Anti Discrimination and Human Rights legislation. An earlier research paper from the Northern Ireland Assembly provides details of an example of how this legislation has impacted on people with Autism. [71]

> *A case heard before the Employment Tribunal in England highlighted the potential difficulty for persons with autism seeking to meet the statutory definition of having a disability. The case involved a person with Asperger's Syndrome and Autism and the Employment Tribunal was required to rule on whether or not he satisfied the statutory definition of disability. The Employment Tribunal noted the absence of a specific factor in schedule 1 para 4 relating to conditions adversely affecting a person's ability to communicate or interact with other people and concluded that the applicant's conditions did not satisfy the statutory definition of disability.*
>
> *The Disability Rights Commission notes that the case presented an opportunity for the Employment Appeal Tribunal to clarify an unclear area of the law and thereby determine whether a significant number of people with Autism and Asperger's syndrome have effective protection under the DDA as it is presently framed. The DRC also argued that the case provided a vivid example supporting its recommendation for legislative change to incorporate the ability of a person to communicate and interact with others within the factors listed in Schedule 1, paragraph 4. The decision of the ET was appealed to the Employment Appeal Tribunal and the appeal, which was heard in January 2004, was successful. The EAT held the condition fits within the ability to understand, which covered understanding of broad human social interaction. The case was remitted back to the original Employment Tribunal to consider whether the adverse effect of the condition on the client's ability to understand is adversely affected to a substantial extent. However, a settlement was reached prior to the hearing.*

The fact that the case was settled means that the precedent is not established and the confusion is allowed to continue.

LEGISLATIVE OPTIONS

The first question to ask in relation to legislation is: What do you want the legislation to do? In answer to this there are three main options. Firstly there is information gathering legislation designed to establish information on ASD as in the US Combating Autism Act. This type of legislation ensures that research is being funded and carried out to map ASD, to monitor prevalence, to understand its causes and to highlight best practice in support and treatment. Another example is the Adults with Autism Bill before Westminster which would obligate local commissioning bodies to

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[71] http://assist.assemblyni.gov.uk/services/rsrchlib/research/reports/dept/hssps/2008/foster7308.pdf

maintain a register of people with Autism. Although this has been enshrined in legislation in the US, in other countries research centres and information gathering exercises have been set up without using legislation. As part of the strategy in Wales a Chair of Autism has been created and the first year of the strategy is devoted to collating information on people with Autism. In addition the Department for Education and Skills has established the Autism Research Co-ordination Group to collate research and inform policy. Indeed in Northern Ireland money has been provided to set up the Middletown Centre for Autism.

Secondly legislation can be sought to counter discrimination against people with ASD including filling the gaps where existing legislation is believed not to be adequate. The ASD lobby feel that given the social / communication aspect of ASD that it does not fit neatly into the disability definition of the Disability Discrimination Act. The example noted above of the case before the Employment Tribunal exemplifies this problem. The DDA defines disability as “a physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities”. A person with autism who seeks to rely on the DDA and related legislation will, therefore, have to meet this definition of disability. The question still to be answered is; would it be best to broaden out the disability definition to include ASD either by naming it or by including a better description of social and communicative disability. The problems facing this are that to name ASD in the legislation may be seen as singling out ASD above other disorders or disabilities and that to broaden out the description of social and communicative problems may be difficult to define and open up the legislation too far.

The third option is to create legislation which obligates government to provide Autism services or which establishes a specific Autism Strategy. Sweden is recognised as a country with a comprehensive system of support for people with ASD; their system is based around extensive public spending on social measures but also through a legislative base. Sweden’s 1993 Act concerning “Support and Service for Persons with certain Functional Impairments” specifies Autism within the Act and gives them the right to special measures and support which offers them “equality of living” (a copy of the Act is attached at appendix 3). The same issues apply to this option as to option two; that Autism is being singled out. In addition it can provide a larger financial burden on departments. Other examples of this type of legislation are the *Adults with Autism* Bill at Westminster and the *Expanding the Promise for Individuals with Autism* Act in the United States.

The view of the author of the Independent Review, Lord Maginnis, is that Autism legislation would not be his first choice. In a debate in the House of Lords, Lord Maginnis points out that: [72]

> *My number two proposal would be that, if we cannot achieve consistency and efficiency by persuasion, the Government must legislate specifically for autism. I hope that that will not be necessary.*

As evident from Lord Maginnis’s statement, a reason for enacting ASD specific legislation is because the extra help needed will not be provided without it. As mentioned earlier the creation of a strategy can take time and getting departments to work together on a strategy creates problems of coordination and cross-departmental working. From a Northern Ireland perspective, the specific nature of the coalition government means that getting agreement across departments is made more

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[72] http://www.publications.parliament.uk/pa/ld200708/ldhansrd/text/80319-0012.htm.

difficult. To circumvent this constraint legislation agreed by the executive may be a more direct method of providing departmental buy-in for improving services for people with ASD.