Proposal for a Scottish Autism Strategy Bill

Public Consultation

Hugh O'Donnell MSP
January 2010
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Foreword

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In the years since the Scottish Parliament was reconvened in 1999 successive Scottish administrations and individual members have taken forward legislation intended to improve our individual and collective lives.

Much of that work has focused on helping marginalised, vulnerable or neglected sections of society, and it is in that spirit I present my proposal for a Scottish Autism Strategy Bill.

I was for many years interested and involved in the field of autism outside parliament and have continued to pursue this interest through parliamentary activities.

I have become increasingly aware of the need for a ‘first step’ on the road to equality for those who have autism and their carers. By introducing a national strategy for autism services in Scotland, this Bill can be that first step.

It is with this in mind that I commend this proposal to you.

With best wishes.

January 2010
INTRODUCTION

- I intend to prepare for introduction a Scottish Autism Strategy Bill in the Scottish Parliament.

- This Bill will seek to place on the Scottish Government a statutory duty to prepare and publish a strategy to meet the needs of children and adults with autism; consult with appropriate organisations and people; and issue statutory guidance to local authorities and health boards on their services for children and adults with autism.

- At present Scotland is the only part of the United Kingdom without a national autism strategy. In Wales, the Assembly adopted the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales in 2008. The Northern Ireland Executive launched their ASD Strategic Action Plan in 2009. Also in 2009 the Autism Act received Royal Assent, setting a legislative framework for the Department of Health’s autism strategy in England, giving it statutory backing as well as placing duties on local authorities. This Bill will ensure that Scotland does not lag behind in terms of a national policy for people with Autism.

- Owing to a lack of a national autism strategy in Scotland people with autism and their carers face something of a postcode lottery in terms of service provision. This Bill will ensure national standards of service and provision and guidance to local providers.

- My Bill has the potential to bring many positive changes to the lives of adults and children with autism and their families. By ensuring that the Scottish Government identifies the range and standards of services that should be made available to them – in consultation with service users and providers – people with autism will be better supported in terms of the provision of diagnostic services, the identification of children and adults with autism locally, the assessment of their needs, the planning and provision of services and the training of staff.

- This consultation paper sets out the background to the issue, makes the case for change and explains the way forward. After reading it, you are invited to respond to a series of questions to assist me in finalising the approach I will then take.
What is autism spectrum disorder?

Autism is a lifelong developmental disability that affects how 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.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.

The three main areas of difficulty (sometimes known as the 'triad of impairments') 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.

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 often have accompanying learning difficulties, including dyslexia.

There are around 50,000 people in Scotland with autism spectrum disorder (including Asperger syndrome), that's about 1 in 100 people. If we include their families autism touches the lives of over 200,000 people every day.
On 12th November 2009 the Autism Act received Royal Assent. It sets a legislative framework for the Department of Health’s autism strategy in England, giving it statutory backing as well as placing duties on local authorities.

The Welsh Assembly adopted the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales in 2008 to drive improvements forward for children, young people and adults in health, social services and education. It also extends to cover the areas of housing, leisure and society in general.

The Northern Ireland Executive launched a similarly titled ASD Strategic Action Plan in 2009 aimed at delivering significant improvements in services for people of all ages affected by autism including their families.

**Autism and Scotland**

**Education**

In 2006 HM Inspectorate of Education (HMIE) expressed concern that many education authorities across Scotland were unable to quantify the numbers of pupils with autism. Few authorities were found to be effectively developing policy and planning to meet the needs of children and young people with autism and a majority of teachers and non-teaching staff in mainstream schools did not have a sufficient understanding of the condition.

Schools have a legal duty under the Special Educational Needs and Disability Act 2001 to make ‘reasonable adjustments’ for pupils who need extra support with learning. Many families however continue to struggle to get support for children with autism. The most recent report from the President of the Additional Support Needs Tribunal Scotland highlighted that almost half of all appeals to the Tribunal concerned children or young people with autism. Yet this group only makes up 12% of the pupils identified as having additional support needs.

HMIE called for a more strategic approach to planning for the needs of pupils with autism. The Scottish Government has responded by issuing the ‘Autism Toolbox’ to every school but still needs to address strategic planning issues and how implementation of the Toolbox will be assessed.

The Scottish Government and education authorities have been asked by HMIE to become more strategic in planning to meet the needs of pupils with autism.
Transition to adulthood

People with autism find it difficult to understand and cope with change yet we all go through significant times of transition in our lives. If people with autism are to be adequately supported in coping with change then times of transition need to be well prepared for. A failure to adequately plan for a major transition, for example leaving school to using adult services, has a hugely detrimental impact on the wellbeing of someone with autism.

The ‘More Choices More Chances’\(^1\) policy to reduce the proportion of young people without an acceptable post-school destination aims to help those with support needs and disabilities. In addition national clinical guidelines state there should be multiagency life long planning for people with autism.

Successful transition planning relies on a number of key strategic agencies co-ordinating together and involving a young person and their family at the centre of their planning. Transition planning needs to take account of the fact that a young person with autism will need time to make adjustment and that their future health and wellbeing is at stake. Sadly for many children and young people transitions are a fraught time especially when various agencies fail to take part.

Challenges in organising care and support

Getting care and support as an adult relies on an assessment of needs, carried out by health, education and social work professionals to identify individual need. Everyone with care needs should be able to expect to receive an assessment, and referral to appropriate support.

Many adultswith higher functioning autism, such as Asperger syndrome, are often not considered for support services. For many people with autism the only available choices are learning disability or mental health services, even though autism is different from either of these conditions. Few autism-specific services have been developed with the result that adults are receiving care services that aren’t meeting their needs, or left without any support at all.

Families are often left to meet all or most of the care needs of adults with autism and face real financial hardship and pressure on relationships.

Many of the professionals responsible for carrying out assessments have not been trained in autism. Training is often uncoordinated as is the planning of appropriate services to support people with autism.

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\(^1\)More Choices, More Chances (MCMC) was published in June 2006 and endorsed by the Scottish Government following the Election in May 2007. Of some 32,000 young people in Scotland not in education, employment or training around 24,000 need additional support to be able to move into learning or employment. MCMC aims to ensure that that young people are able to access the universal services from which they should benefit, aligning mainstream systems to cater for all young people including those who need additional support.
There remain significant gaps in service planning to identify the scale of need of people with autism and also to co-ordinate effective cross-agency working on service development.

**Employment**

There are many people with autism capable of working in a wide variety of jobs and who may have specific skills to do so. But those who are in employment can face difficulties socialising in the workplace and being accepted when their behaviour is seen as odd or challenging, or they may find it difficult to work in an environment which requires a lot of flexibility.

Many others with autism need support with getting ready for employment and then help with getting a job. Being able to work is a very important aspiration for many adults with autism and a significant effort is needed to improve on the poor rates of employment for people with autism.

The Scottish Autism Services Network has highlighted a lack of available data on employment. Previous government research has highlighted that poor employment rates and support for people with conditions such as autism has yet to impact as an issue for a significant number of employers.

**Barriers for People with Autism**

Scottish Government advice on commissioning services says that a lack of diagnosis of autism spectrum disorder should not be a barrier to getting support from a range of service providers. But for many it is, notwithstanding the SIGN clinical guidelines\(^2\), a diagnosis is often the key to services.

Even with a diagnosis it is difficult to get support because services do not fully recognise and meet people’s needs. Learning disability and mental health services are not set up for the needs of people with autism and may not accept people who have an autism diagnosis.

There is non-statutory guidance on commissioning services for people with autism but across Scotland there is a very real ‘postcode lottery’ of provision with many areas of the country not providing a basic level of service.

Gaps in provision exist in diagnostic services, child and adolescent mental health services, school support, adult services and support into employment. Many families and carers also struggle to have their needs for respite breaks and support met.

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\(^2\) SIGN Clinical guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. Guidelines provide recommendations for effective practice in the management of clinical conditions where variations in practice are known to occur and where effective care may not be delivered uniformly throughout Scotland.
There are limits to the effectiveness of current initiatives and the often generic strategies in place for developing care and support. This is reflected in the slow progress in developing autism appropriate services across Scotland and the many cases highlighted in Parliament and in the media about the daily struggles people with autism and their families face.

Public authorities need to take a much more strategic approach to autism if they are to begin effective planning. They need to appreciate that meeting the needs of people with this ‘hidden disability’ is also a part of their equality duty and that they must be proactive in meeting those needs.

Costs to people and to society

Evidence is pointing toward significant costs to individuals with autism in terms of their health and wellbeing when they don’t get the right assistance.

The costs to local government and health services of this have been highlighted by the National Audit Office (NAO) in a report on the economic costs of autism. There is a challenge for government to consider the full costs of unmet need and the reliance on more expensive care packages compared with the costs of early intervention, which could potentially lead to significant savings.

Evidence also shows that the right care and support, provided at the right time to someone with autism, can really change their prospects and allow them to live full and independent lives especially if they can be supported into employment.

Public finances will face significant pressures over the coming years but many people with autism will be left exceptionally vulnerable if support is removed from them. A national strategy would ensure that limited resources are used to the greatest effect.

An Appendix to this document sets out key statistics in relation to the impact and costs of inadequate support for people with autism.
THE CASE FOR A SCOTTISH AUTISM STRATEGY BILL

To deliver the Scottish Government’s Strategic Objectives

As set out above, people with autism across Scotland are facing significant challenges in leading independent and full lives. A national ASD strategy, backed by enabling legislation to give it statutory force, would deliver the Scottish Government’s strategic objectives and a range of national outcomes such as healthier lives, employment opportunities, supporting public services and reducing inequalities.

Such an approach would not only bring Scotland into line with developments across all nations of the United Kingdom, it would lead to improvements in understanding how national outcomes and Single Outcome Agreements can be used to deliver better outcomes for people with autism.

To tackle unmet Need

Accessing education at all levels is particularly difficult for those who have autism and Asperger syndrome.

Many people with autism have greater need for support as a result of a failure to provide appropriate support when it is needed. Post-school transition arrangements are often so poor young people with autism are left without appropriate support into further or higher education, employment support or care.

To reduce Costs

The NAO has identified the true costs of autism services and support at approximately £2.3 billion for Scotland each year. The NAO believes that steps to deliver the right support for adults with autism will save millions of pounds and lead to much better outcomes for people with autism.

NAO believe that if local authorities identify and support just 4% of adults with Asperger syndrome the cost of services will be cost-neutral. The more people who are identified and supported the greater the savings will be.

To improve Service Delivery

There are significant difficulties in local authorities accurately recording the numbers of people with autism.

Local authorities and health boards are not commissioning enough appropriate services for people with autism.

Key professionals such as GPs need much better training, especially as they act as gatekeepers to other services.
PROPOSAL FOR A SCOTTISH AUTISM STRATEGY BILL

The proposal is for a Scottish Autism Strategy Bill that would place duties on the Scottish Government, local authorities and health boards to improve support for both adults and children with autism:

The terms of the proposal would place a statutory duty on the Scottish Government to:-

• prepare and publish a strategy to meet the needs of children and adults with autism;

• consult with appropriate organisations and people;

• issue statutory guidance to local authorities and health boards on:-
  • the provision of diagnostic services;
  • the identification of children and adults with autism locally;
  • the assessment of their needs;
  • the planning and provision of services;
  • the training of staff;
  • leadership at local level.
HOW TO RESPOND

Thank you for reading this consultation paper. I hope you have been persuaded that there is a powerful and clear case for a national autism strategy to improve the lives of people with autism in Scotland.

You are now invited to respond to this consultation paper by answering the questions below and making any other comments that you consider appropriate.

Q1. Would people with autism in Scotland benefit from a national strategic approach?

Q2. Is a Scottish Autism Strategy Act needed to make a national ASD strategy effective?

Q3. Are the duties proposed appropriate to enabling a national ASD strategy for Scotland?

Q4. Are the duties proposed appropriate to guide local agencies to take a strategic approach to autism services in their area?

Q5. Are there any other comments you wish to make about this proposal?

Responses, which should be submitted by Tuesday 30 March 2010, should be sent to:

Hugh O’Donnell MSP
Scottish Parliament
Edinburgh EH99 1SP

Email: hugh.o’donnell.msp@scottish.parliament.uk

Please make it clear whether you are responding as an individual or on behalf of an organisation.

If you wish your response to be confidential, please say so. Otherwise it will be available for public inspection, in accordance with the principles of transparency and freedom of information. Confidential responses will be included in any summary or statistical analysis but this will not reveal the identity of any respondent who has requested confidentiality.
Additional copies of the paper or alternative formats can be requested using the contact details above and calls via Typetalk are welcome. An on-line copy is available on the Scottish Parliament website The Scottish Parliament: - Bills - Proposals for Members' Bills.

Contact for further Information

For further information please contact Hugh O'Donnell MSP on 0131 348 5796
Appendix – Key Statistics

‘Commissioning Services for People on the Autism Spectrum’ Scottish Government 2008

- Up to 40% of people with autism will be diagnosed with a learning disability.
- Identifies lack of clear ownership for service development across health and social care.

National Audit Office- Supporting People with Autism Through Adulthood, June 2009

- Study by researchers at King’s College London estimated that autism costs the UK economy around £28.2 billion a year (£25.5 billion for adults and £2.7 billion for children)
- There are two key areas where the effectiveness of existing services can be improved: better strategy and planning, based on good information and raising levels of knowledge and awareness of the nature of autism and the potential needs of autistic people.
- We estimate that if such services identified and supported around four per cent or more of the adults with high-functioning autism in their local area, they could become cost-neutral across public spending as a whole over time
- A six per cent identification rate could lead to potential savings of £38 million per year, and an eight per cent rate to savings of £67 million


- 28% of individuals report a diagnosis of something in addition to AS.
- 64% of individuals reported that the diagnosis was either very hard or somewhat problematic to obtain.
- Identified a lack of consistency across the country for referral routes and levels of expertise.
- 86% of individuals received no support or not enough support post diagnosis.
- Only 21% got any support in getting a job.

The Development of a National Training Framework for Autistic Spectrum Disorders, 2004

- Around 4,600 school age children fall within the spectrum of autistic disorders. (McGregor and Campbell, 2001)
- Only 50% of specialist teachers in Scotland have had autism specific training. Evidence suggests that even moderate increases in
educational provision could potentially result in major savings in later living costs.

Scottish Government Health: eSay Data Collection of Learning Disability and ASD. Run by the Scottish Consortium for Learning Disabilities

- 2009 was the first year information was requested of local authorities on the number of adults with autism.
- Four local authorities were unable to respond with this information and others unable to respond completely.
- Information missing on 47% of the people covered, many will be adults with an ASD diagnosis. It also only covers adults known to learning disability services.

Education for Pupils with Autism Spectrum Disorders, HM Inspectorate of Education, 2006

- For pre-school children only half of all education authorities made specialist provision.
- In Primary Schools around 29% of pupils with ASD were in specialist units, 67% of these children having been medically diagnosed with ASD.
- Just fewer than 60% of education authorities made provisions in specialist units for children with ASD in secondary schools. 28% of pupils with ASD in secondary schools were in specialist units.


- Reason for Additional Support – Autistic Spectrum Disorder: 5, 254 pupils

Destinations for school leavers for pupils with ASD, Scottish Government, 2007/08.

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<th>14 %</th>
<th>(32% pupils without additional support need)</th>
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<tr>
<td>FE</td>
<td>57%</td>
<td>(24%)</td>
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<tr>
<td>Training</td>
<td>4%</td>
<td>(5%)</td>
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<tr>
<td>Employment</td>
<td>10%</td>
<td>(26%)</td>
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<tr>
<td>Voluntary Work</td>
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<td>(0%)</td>
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<tr>
<td>Unemployed active</td>
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<tr>
<td>Unemployed inactive</td>
<td>4%</td>
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<tr>
<td>Unknown</td>
<td>1%</td>
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Attainment in Higher Education and Destination of Leavers 2007/08, Scottish Government

0.1% of students recorded as having Autistic Spectrum Disorder (145 students).
I Exist – The message from adults with autism in Scotland, 2008, NAS.

- 31% of adults with autism have developed severe mental health problems.
- 54% of adults with autism feel they do not have enough support to meet their needs, for adults with Asperger syndrome and high-functioning autism it rises to 64%.
- Only 34% of adults with autism have received an assessment of their needs since they were 18.
- 41% of adults with autism live at home.

Don’t Write Me Off, 2009, NAS

- 15% of adults with autism have a full-time job.
- 79% of those on Incapacity Benefit want to work.
- A third are currently living without a job or benefits, over half have spent time with neither a job nor benefits, some for over ten years.