

# **AUTISM (SCOTLAND) BILL**

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## **POLICY MEMORANDUM**

### **INTRODUCTION**

1. This document relates to the Autism (Scotland) Bill introduced in the Scottish Parliament on 26 May 2010. It has been prepared by Hugh O'Donnell MSP, who is the member in charge of the Bill, to satisfy Rule 9.3.3A of the Parliament's Standing Orders. The contents are entirely the responsibility of the member and have not been endorsed by the Parliament. Explanatory Notes and other accompanying documents are published separately as SP Bill 44–EN.

### **POLICY OBJECTIVES OF THE BILL**

2. The objective of the Bill is to ensure that the Scottish Government has 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.

3. There are an estimated 50,000 people in Scotland with autism or Asperger syndrome (a form of autism).

4. Research by National Autistic Society<sup>1</sup> Scotland demonstrates that many people with autism face significant problems in getting help and that service providers have a poor idea of what their needs are and what outcomes are being achieved for people with autism. Delays in putting support in place can have a significant detrimental impact on people's physical and mental well-being.

- Only 13% of adults with autism are in full-time employment, although with the right support many more could be in work.<sup>2</sup>
- Many children face exclusion from school, nearly a quarter of these illegal informal exclusions, often because of a lack of support at school.<sup>3</sup>
- 57% of parents and carers say that a lack of timely support has resulted in their son or daughter having higher support needs.<sup>4</sup>

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<sup>1</sup> Written submission by National Autistic Society Scotland to the member's consultation on his proposal

<sup>2</sup> *ibid*

<sup>3</sup> *ibid*

<sup>4</sup> *ibid*

5. The need for a strategic approach to meeting the needs of people with autism has been recognised in England, Wales and Northern Ireland.

6. In November 2009 the Autism Act received Royal Assent, applying to England. In Wales, Ministers have indicated that in the review of the Welsh autistic spectrum disorder strategy that they would consider whether regulation is required to deliver their strategy. In Northern Ireland the cross-party autism group in the NI Assembly is considering proposals for regulation.

7. There has been a raft of policy initiatives on autism in Scotland in recent years. Yet research continues to show that many areas are not considering the needs of people with autism. Services are simply not available, and people with autism across Scotland are not receiving the support they vitally need. One in three families has to resort to tribunal to get support and nearly a quarter have to go outside their local area to get the right services.

8. Legislation is the only way to ensure that there is effective planning to meet the needs of people with autism both nationally and in every local area in Scotland.

## **BACKGROUND**

9. There is no legislation in Scotland specifically relating to people with autism spectrum conditions. However, a number of Acts, both Scottish and UK, are related to the proposals contained in the Bill. This existing legislation does not make specific reference to developmental conditions such as autism and consequently that condition is frequently overlooked when applying the terms of those existing Acts.

10. A synopsis of each of the current Acts is provided below.

### **Social Work (Scotland) Act 1968**

11. This places the organisation and provision of welfare services for “persons in need” with local authorities. It introduced a duty on local authorities in Scotland to “promote social welfare” and provided the basic structure for contemporary social work in Scotland. The chief social work officer has several key statutory functions which involve overseeing the provision and purchase of social work services.

### **National Health Service and Community Care Act 1990**

12. This Act was the first piece of legislation to introduce a specific statutory framework for community care and it forms the cornerstone of community care law. It aimed to oversee the policy aim of shifting the balance of care from hospitals and institutions to community based settings. It was also an attempt to bridge the gaps in community care law. It placed a duty on local authorities to assess the need for “community care services” and enhanced their duty to secure the provision of welfare services. It applied to the elderly, disabled and those suffering from mental/physical health problems and so extended provision to those omitted in the Chronically Sick and Disabled Persons Act 1970.

### **Children (Scotland) Act 1995**

13. Among other things this requires local authorities to protect and promote children's welfare and to prepare children's services plans. It gave local authorities in Scotland additional duties and powers to respond to the requirements of children "in need" which includes children with disabilities.

### **The Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002**

14. This requires education authorities in Scotland to ensure that strategies are in place to improve access to the curriculum and to the physical environment, and to improve communication with disabled pupils. The strategies should be available for parents to see and are monitored by Her Majesty's Inspectorate of Education (HMIE) in their routine inspections of schools and education authorities.

### **Education (Additional Support for Learning) (Scotland) Act 2004**

15. This created a broad definition of additional support needs which includes all children, who, for whatever reason, require additional support for their education. The local authority must assess those children for whose education it is responsible and make adequate and efficient provision for the additional support required. The Act sets out the criteria for co-ordinated support plans (CSPs), but children without CSPs must also be provided with support. A statutory code of practice provides further guidance. The revised code of practice (including guidance on the criteria for CSPs) is due to be laid in the Parliament very soon and will be considered by the Education, Lifelong Learning and Culture Committee.

### **Adult Support and Protection (Scotland) Act 2007**

16. Part 1 of the Act introduced new provisions for the protection of adults at risk of abuse, including inspection and investigation powers for local authorities and a range of interventions. Part 2 of the Act amended the Adults with Incapacity (Scotland) Act 2000, with the aim of simplifying and streamlining the protections for adults with incapacity and improving access to them. Part 3 of the Act made a number of amendments and repeals to the Social Work (Scotland) Act 1968, in the areas of ordinary residence, care home fees and direct payments.

## **CONSIDERATION OF POLICY ISSUES**

17. In 2006 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.

18. 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 for Scotland<sup>5</sup> 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.

19. 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.

20. 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. Problems that could be addressed by a more strategic approach are set out below.

### **Transition to adulthood**

21. 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.

22. The *More Choices More Chances*<sup>6</sup> 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 multi-agency, life-long planning for people with autism.

23. Successful transition planning relies on a number of key strategic agencies.

### **Employment**

24. 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.

25. 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.

26. The Scottish Autism Services Network has highlighted a lack of available data on employment. Previous government research has highlighted that poor employment rates and

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<sup>5</sup> Fourth Annual Report of the President of the Additional Support Needs Tribunals for Scotland (2008-2009)

<sup>6</sup> <http://www.scotland.gov.uk/Publications/2006/06/13100205/0>

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**

27. 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<sup>7</sup> clinical guidelines. A diagnosis is often the key to services.

28. 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.

29. 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.

30. 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.

### **Unmet needs**

31. Accessing education at all levels is particularly difficult for those who have an autistic spectrum disorder.

32. Many people with autism have greater need for support as a result of a failure to provide appropriate support when it is needed.

33. Post-school transition arrangements are often so poor that young people with autism are left without appropriate support into further or higher education, employment support or care.

### **Costs**

34. The National Audit Office (NAO)<sup>8</sup> 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.

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<sup>7</sup> 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

<sup>8</sup> <http://www.nao.org.uk/publications/0809/autism.aspx>

35. 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.

### **Service delivery**

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

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

38. Key professionals such as general practitioners need much better training, especially as they act as gatekeepers to other services.

### **Delivery of the Scottish Government's strategic objectives**

39. As set out above, people with autism across Scotland are facing significant challenges in leading independent and full lives. A national autistic spectrum disorder 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.

40. 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.

### **ALTERNATIVE APPROACHES**

41. Amongst the 170 responses to the consultation, there were 19 respondents who did not support the strategy as envisaged in the Bill. Amongst this group there was a body of opinion that expressed a view that, while there would be merit in an autism strategy, it did not need legislative force. It is considered, however, that in order for the Bill to effect change for people on the autistic spectrum, the strategy needs some legislative force.

### **CONSULTATION**

42. The consultation document accompanying the draft proposal for the Scottish Autism Strategy Bill was issued on 6 January 2010 and the consultation ran until 30 March 2010.

43. The consultation document was made available on the Scottish Parliament website<sup>9</sup>. A summary of the responses can also be found there.

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<sup>9</sup> At <http://www.scottish.parliament.uk/s3/bills/MembersBills/index.htm>

44. 317 copies of the consultation document were initially issued to organisations and MSPs. Further copies were posted or e-mailed in response to individual enquiries.

45. There were 170 responses to the consultation document. These can be categorised within the following groups:

- individuals 114
- third sector 33
- local authorities 13
- public healthcare organisations 4
- private companies 2
- professional bodies 2
- unions 1
- academics 1
- police bodies 1

46. As noted above, there were 170 responses to the consultation. Of these, 147 supported the proposal, 19 expressed opposition to the proposal and 4 neither opposed nor supported the proposal.

47. Support for the proposal was drawn from across all groups. It is of particular relevance to note the almost universal support for the proposal from individuals. All of the individuals responding had considerable experience of autism spectrum disorders with the majority either being on the spectrum themselves or caring for someone who is.

## **EFFECTS ON EQUAL OPPORTUNITIES, HUMAN RIGHTS, ISLAND COMMUNITIES, LOCAL GOVERNMENT, SUSTAINABLE DEVELOPMENT ETC.**

### **Equal opportunities**

48. The Bill will have no adverse effect on equal opportunities. It will on the contrary create an environment conducive to giving people on the autistic spectrum equality of opportunity.

### **Human rights**

49. The Bill will have no adverse effect on human rights. It will on the contrary create an environment conducive to improving the human rights of people on the autistic spectrum.

### **Island communities**

50. It is not anticipated that this Bill will have any differential impact on island communities. The Bill seeks to forge consistency of standards and provision of services to people with autistic spectrum conditions across Scotland, so there should be no differential impact on any particular area of Scotland.

**Local government**

51. There will be minimal if any direct impact on local government. The financial and resource impact of this Bill is expected to be minimal.

**Sustainable development**

52. This Bill will have no negative effects on sustainable development. Its effects will be positive as it will promote social inclusion by increasing the opportunities for children and adults with autistic spectrum conditions.



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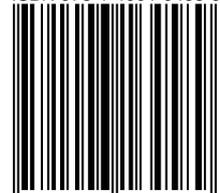
## **POLICY MEMORANDUM**

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