

SPICe Briefing

Autism (Scotland) Bill

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The [Autism \(Scotland\) Bill \(SP Bill 44\)](#) (The Bill) was introduced as a Members' Bill in the Scottish Parliament on 26 May 2010 by Hugh O'Donnell MSP. The purpose of the Bill is to place a statutory duty on the Scottish Government to prepare and publish an 'autism strategy' to meet the needs of young people and adults with autistic spectrum conditions, and to produce guidance for local authorities and NHS bodies to implement the autism strategy.

This briefing explains what the 'autistic spectrum' is and examines statistics on its prevalence in the UK. It summarises responses to the Member's consultation on the proposal for an autism strategy, considers the financial and legal implications of the Bill and provides an overview of existing legislation and policy relating to individuals on the autistic spectrum. It outlines the recommendations made in the Scottish Government's draft Autism Strategy consultation and finally, the briefing provides a summary of the written evidence received by the Scottish Parliament Education, Lifelong Learning and Culture Committee on the Bill.



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EXECUTIVE SUMMARY

- The [Autism \(Scotland\) Bill \(SP Bill 44\)](#) (plus accompanying documents) was introduced in the Scottish Parliament on 26 May 2010 by Hugh O'Donnell MSP. The purpose of this Members' Bill is to place a statutory duty on the Scottish Government to prepare and publish an 'autism strategy' to meet the needs of young people and adults with autistic spectrum disorders; and to produce guidance for local authorities and NHS bodies to implement the autism strategy. The Bill also provides for these bodies to have a 'duty to have regard to' the guidance produced
- Autism is one of a group of conditions that makes up the autistic spectrum. It is a developmental disability that affects how a person communicates and socially interacts with the rest of society. There are three main areas of difficulty that people on the autistic spectrum may share, which are: difficulty with social communication, difficulty with social interaction; and difficulty with social imagination. The extent to which individuals display the range of characteristics associated with the autistic spectrum varies greatly, as does the way in which the condition affects an individual's life
- Research into the prevalence of autism to date has been limited to specific populations, with no 'central register' of people on the spectrum and no robust survey of the adult population. However, the most recent research, based on studies examining the prevalence of these conditions (in children) has estimated that approximately 1% of the population of the UK fall on the autistic spectrum. This represents about half a million people in the UK and around 50,000 in Scotland
- Mr Hugh O'Donnell MSP consulted on his [Draft Proposal for an Autism Bill](#) between 6 January and 30 March 2010 (O'Donnell 2010). There were 170 responses to this consultation, most of which were from individuals on the autistic spectrum, or their families and carers. The vast majority of respondents were in favour of the introduction of a National Strategy, and legislation to underpin it. However, some respondents argued that there was no need for legislation, that the statutory duties outlined were not detailed enough and were not costed. Others argued that consultation would be vital to the process, as would be sufficient funding for provision of services and sufficient training for professionals working with people with ASD, particularly for diagnostics and early interventions
- The [Bill's Financial Memorandum](#) (FM) estimates the cost of the Bill at approximately 'no more than £5000' for the Scottish Government to prepare, consult on, and publish an autism strategy; and approximately £1500 per local authority or NHS body to respond to the autism strategy consultation. The FM refers only to the financial implications of the process of developing a strategy and guidance, and does not infer any costs relating to the implementation of such a strategy or guidance
- There is currently no specific legislation in Scotland that relates to autism spectrum conditions. However, there is existing UK and Scottish legislation that would be applicable to the rights and needs of individuals with additional support needs and disabilities, such as those on the autistic spectrum

- An Autism [Spectrum Disorder \(ASD\) Reference Group](#), consisting of users, carers and professionals was established in 2002 and operated until 2008 to take forward the recommendations in the Public Health Institute of Scotland (PHIS) Needs Assessment of those with ASD, originally commissioned by Scottish Ministers. The aim of this study was to provide information for service commissioners on the best available knowledge about autism spectrum disorders and current service provision in Scotland and guidance on how these services might better meet the needs of those with autism spectrum disorders in the future. It focused on 'ideal' services for people with an ASD concentrating on diagnosis and assessment, as well as looking at services currently available in Scotland (Scottish Government, 2010a).
- The Scottish Government has agreed that the work of the ASD group now needs to be refreshed due to increasing public expectation, and that a revised 'National Autism Strategy' could be achieved without the need for the introduction of new legislation. It argued that many of the issues the Autism (Scotland) Bill is seeking to address are already being delivered through the specific work of the ASD reference group and broader Government initiatives
- On 12 November 2009, the UK Parliament's [Autism Act 2009](#) received Royal Assent. This Act has placed a duty on the Secretary of State to publish an autism strategy for England by 1 April 2010, and to issue related guidance to local authorities and NHS bodies by 31 December 2010. It prescribes that the Strategy will be for meeting the needs of adults on the autistic spectrum. In 2008 and 2009, the Welsh Assembly Government and the Northern Ireland Executive also published National Strategic Action Plans for individuals with ASD.
- A raft of detailed evidence was provided to the Committee, covering the broad spectrum of issues currently faced by individuals with ASD. Many respondents provided extensive feedback on the effectiveness of existing policies and legislation and highlighted specific examples of good practice, as well as identifying gaps.
- One of the key issues raised in evidence received by the Committee was the need for more detailed research, in particular to identifying the population with ASD and mapping/assessing the needs of those individuals on a national scale.
- Whilst some good examples of the existing support available were identified, several gaps in service provision, specific to meeting the needs of individuals with ASD were raised, including: access to diagnosis and training of professionals, early intervention programmes, transition support from childhood to adult services, employment services for adults with ASD, advocacy services, support in the criminal justice system, leisure and transport
- Many of the individuals, families and carers, as well as groups, highlighted that individuals with ASD could contribute greatly to the economy and society, if provided with the correct support. Whilst gaps in support exist, this opportunity is being lost
- The introduction of a national strategy was generally welcomed, as a means of providing a cohesive approach and of encouraging better multi-agency working. However, there was disagreement between respondent groups on the need for legislation to underpin such a strategy, with individual respondents, autism groups and other voluntary/third sector organisations favouring legislation and local authorities arguing that legislation would be counter-productive

INTRODUCTION

The [Autism \(Scotland\) Bill \(SP Bill 44\)](#) (plus accompanying documents) was introduced in the Scottish Parliament on 26 May 2010 by Hugh O'Donnell MSP. The purpose of this Members' Bill is to place a statutory duty on the Scottish Government to prepare and publish an autism strategy to meet the needs of young people and adults with autistic spectrum conditions, and to produce guidance for local authorities and NHS bodies to implement the autism strategy. The Bill also provides for these bodies to have a 'duty to have regard to' the guidance produced.

Mr O'Donnell consulted on his draft proposal for a Members' Bill between 6 January and 30 March 2010 (O'Donnell 2010). There were 170 responses to his proposal and a Summary of Consultation Responses was published in April 2010 (O'Donnell 2010a). His final proposal was lodged on 6 April 2010 and received support from a total of 34 MSPs, 20 of whom were from the Scottish Labour Party, 11 from the Scottish Liberal Democrat Party, two from the Scottish Conservative and Unionist Party and one from the Scottish Green Party (O'Donnell 2010b).

The resulting [Autism \(Scotland\) Bill \(SP Bill 44\)](#) (the Bill) was introduced on 26 May 2010. The Bill is currently being considered at Stage 1 by the Parliament's [Education, Lifelong Learning and Culture Committee](#) (The Committee) with Stage 1 consideration due to be completed by 21 January 2011. The Committee issued a [call for written evidence](#) on 7 July 2010, which closed on 8 October 2010. A summary of this evidence is provided later in this briefing. The first oral evidence session on the general principles of the Bill is taking place on Wednesday 10 November 2010.

BACKGROUND

What is Autism?

The [World Health Organisation International Statistical Classification of Diseases and Related Health Problems 2007](#) defines autistic spectrum disorders as follows:

"The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations.

(WHO, 2007)

Disorders on the autistic spectrum are developmental disabilities (including childhood autism, atypical autism, Aspergers syndrome, Rett's Syndrome and Kannern syndrome) that affect how a person communicates and socially interacts with the rest of society. ASD can be diagnosed from before the age of three, but more often than not is diagnosed later in childhood or adult life (POST, 2008). It was first described in 1943 by Leo Kanner, who identified 'early infantile autism' and established a range of characteristics from which autistic spectrum conditions could be diagnosed. His work was shortly followed by the work of Hans Asperger, who a year later had identified a set of similar behaviours that are observed in individuals with what is now commonly known as Asperger's syndrome (National Autistic Society, online). Aspergers Syndrome is also a form of autism. People with Asperger syndrome tend to have fewer issues with speech and often have average or above average intelligence. However, they can still have difficulties processing language (O'Donnell, 2010).

There are three main areas of difficulty that people on the autistic spectrum may share:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination

(National Autistic Society, online)

People on the autistic spectrum often struggle in new or changed environments, which can have a negative effect on their ability to manage in school, work or other public situations, such as using public transport or going to shops. Many people on the autistic spectrum also have additional learning disabilities (such as dyslexia), behavioural conditions (such as tourettes syndrome or attention deficit hyperactive disorder (ADHD)) and/or mental illnesses (most commonly depression or anxiety and in some cases psychosis) (POST, 2008).

The word 'spectrum' is used to describe these conditions, because, although people on the spectrum can experience the three main areas of difficulty outlined above, the extent to which individuals display the range of characteristics associated with the autistic spectrum varies greatly, as does the way in which the condition affects an individual's life (National Autistic Society, online). In addition, the severity of these characteristics can change with age, or can fluctuate at different times and in different circumstances. Some people on the autistic spectrum are able to live relatively independently, whilst others may need specialist support throughout their lives.

Table 1 below was produced by the Parliamentary Office of Science and Technology in 2008 (adapted from a 2003 study in the British Medical Journal) to summarise the key characteristics of the autistic spectrum and the range of behaviours associated with those characteristics:

Table 1: Variation in behaviour across the Autistic Spectrum

Key Characteristics	Presentation can range:	
	From:	To:
Social Interaction	aloof and indifferent	Makes one-sided approaches
Social Communication	No communication	Spontaneous but repetitive
Repetitive behaviour/activities	simple, bodily directed (e.g. face tapping, self injury)	Verbal, abstract (e.g. repetitive questioning)
Other Characteristics		
Formal Language	No language	Grammatical, but long winded, repetitive, literal interpretations
Responses to Sensory information (over sensitivity/insensitivity)	Very marked	Minimal or no unusual responses
Unusual Movements (hand flapping/tiptoe walking)	very marked	Minimal or absent
Special Skills (drawing, wrote memory)	None	One skill at a very high level, very different from other abilities

(POST, 2008)

Autism is often described as a 'hidden disability'. It can be hard to create awareness of autism as people with the condition do not 'look' disabled. Early diagnosis and intervention are usually key to maximising outcomes for individuals. However, some significant barriers are faced by those with ASD. Getting the right care and support at the right time is reliant on correct diagnosis and assessment of needs. It can be difficult to access, as professionals are not

always specially trained to identify those on the autistic spectrum. There are also gaps in the provision of education support services, diagnostic services, mental health services and adult services. People with ASD can struggle in school and to get into employment, as their behaviours can often seem challenging or odd. Statistics from the [National Autistic Society](#) demonstrate the extent of the barriers faced by individuals with ASD:

- Over 40% of children with autism have been bullied at school
- Over 50% of children with autism are not in the kind of school their parents believe would best support them.
- One in five children with autism has been excluded from school, many more than once
- Only 15% of adults with autism in the UK are in full-time paid employment
- 51% of adults with autism in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more
- 61% of those out of work say they want to work
- 79% of those on Incapacity Benefit say they want to work

(National Autistic Society, online)

Prevalence of Autistic Spectrum Disorders (ASD) in the UK and Scotland

In 2001, the Public Health Institute of Scotland (PHIS, now NHS Scotland) carried out a [Health Needs Assessment for Autism Spectrum Disorders](#), which examined studies of the prevalence rates of ASD. The aim of this study was to provide information for service commissioners on the best available knowledge about autism spectrum disorders, levels of service provision in Scotland and guidance on how these services might better meet the needs of children, men and women with ASD (Scottish Government, 2010a). The report indicated a prevalence rate of approximately 60 per 10,000 children, or 0.6% of children.

As part of the recommendations from the PHIS report, the previous Scottish Executive undertook an [Audit of Services for People with ASD](#) in Scotland in 2004. The purpose of the audit was to quantify the prevalence of ASD across Scotland by local authority in order to better plan service provision. Rates of prevalence were identified for both children and adults, although the findings for adults were less robust (Scottish Government 2010a). Table 2 presents the 2004 audit's findings on the rates of prevalence of ASD in children and adults, by age range.

Table 2: Prevalence of ASD in children and adults in Scotland, by age range

	Prevalence (Individuals diagnosed with ASD per 10,000 population)
Children	35
pre-school	42
5-10 years	49
11-15 years	27
16-18 years	16
Adults	
18-24 years	5.1
25-49 years	3.2
50+ years	0.6

(Adapted from Scottish Executive, 2004)

The audit found that the reason the rate of prevalence clearly reduced as age increased was likely to be due to improved diagnosis in recent times. Part of the difficulty in accurately determining the prevalence of ASD in adults is that many adults, particularly of an older generation, may not have had their condition diagnosed. This also explains why the ASD prevalence rate in the pre-school age group was lower, as many individuals on the autistic spectrum will not display any ASD related behaviours or characteristics until after the age of three, so diagnosis is more likely after this age. The rate of prevalence varied greatly by NHS Board area for both children and adults. The findings also demonstrated that:

- 1 out of 5 of children with ASD had learning disabilities
- 1 out of 3 children diagnosed with ASD were diagnosed with Asperger's Syndrome
- 2 out of 3 children diagnosed with ASD were attending mainstream schooling
- More than half of the adults identified with ASD had a learning disability

Research into the prevalence of autism to date has been limited to specific populations, with no 'central register' of people on the spectrum and no robust survey of the adult population. However, studies examining the prevalence of these conditions in children have estimated that approximately 1% of children in the UK fall on the spectrum (Baird, G. et Al, 2006)

Most recent research estimates that over half a million people in the UK fall on the autistic spectrum, approximately 1 in 100 individuals (Knapp, M. et Al, 2007), which equates to approximately 50,000 people in Scotland. Evidence has also shown that conditions on the autistic spectrum are much more prevalent in males than females. Studies examining the ratio of males to females with ASD estimate a range from 3:1, to as high as 15:1 (National Autistic Society Scotland, online).

AUTISM STRATEGIES IN ENGLAND, WALES AND NORTHERN IRELAND

On 12 November 2009, the UK Parliament's [Autism Act 2009](#) received Royal Assent. This Act has placed a duty on the Secretary of State to publish an autism strategy for England by 1 April 2010, and to issue related guidance to local authorities and NHS bodies by 31 December 2010. It prescribes that the strategy will be for meeting the needs of adults on the autistic spectrum by improving service provision by local authorities and NHS bodies. The Act also places a duty on the Secretary of State to keep the strategy and guidance under review and to consult with NHS bodies and local authorities before revising the guidance in any substantial way. The Act also contains provisions that require NHS bodies and local authorities to act under the guidance.

In 2008, the [Autistic Spectrum Disorder \(ASD\) Strategic Action Plan for Wales](#) which sets out a number of key actions and commitments for the development of services for children and adults on the autistic spectrum. It concentrates on better multi-agency working and sets out a plan for mapping and assessing the needs of individuals with ASD in Wales. As part of the action plan, the Welsh Assembly Government will also issue guidance to local authorities on goods and service provision, and minimum service requirements for local education authorities providing education for young people with ASD.

In 2009, the Northern Ireland Executive published the [Autistic Spectrum Disorder Strategic Action Plan 2008/09 to 2010/11](#) intended to deliver significant improvements in services for people of all ages affected by autism, their families and carers. It was launched following an Independent Review of Autism Services, undertaken in 2007. The Review contained a number of recommendations designed to improve health and social care services for both children and adults affected by autism. Again, the focus of the Action plan is upon better multi-agency co-operation. A major action within the ASD Strategic Action Plan was the establishment of a Regional, multi-agency, multi-disciplinary ASD Network Group.

MEMBER'S CONSULTATION AND PROPOSAL

Mr Hugh O' Donnell MSP consulted on his [Draft Proposal for an Autism Bill](#) between 6 January and 30 March 2010 (O'Donnell 2010). The proposal summarised the key barriers that individuals with ASD currently face, and proposed that a Scottish Autism Strategy be introduced to:

1. Deliver the Scottish Government's Strategic Objectives and 'National Outcomes' relating to healthier lives, employment opportunities, supporting public services and reducing inequalities, through a national autism strategy that was enabled by legislation and backed by statutory force
2. Bring Scotland into line with developments in the rest of the UK
3. Tackle unmet need, particularly for accessing education, and appropriate support in the transition from childhood to adulthood (support into further or higher education, employment support or care)
4. Reduce the 'true costs of autism' through early intervention and appropriate provision of care to individuals with ASD
5. Improve service delivery, in terms of local authority identification and recording the numbers of people with ASD in their area, the provision of appropriate services by local authorities and NHS bodies; and the provision of training to key professionals involved in the diagnosis, assessment and support of individuals with ASD

There were 170 responses to the consultation and a [Summary of the Consultation Responses](#) was published in April 2010 (O'Donnell 2010a).

Summary of Consultation Responses

The vast majority (67%) of the respondents to Mr O'Donnell's consultation were either individuals on the autistic spectrum, or people that support someone with ASD. Table 3 below shows the breakdown of consultation respondents as provided in the summary of consultation responses.

Table 3: Respondents to the Member's Consultation by Respondent Group

Respondent Group	Number of Respondents	% of total respondents
Individuals	114	67
Third Sector	33	19
Local Authorities	13	8
Public Healthcare Organisations	4	2
Private Companies	2	1
Professional Bodies	2	1
Unions	1	1
Academics	1	1
Police Bodies	1	1

(adapted from O'Donnell, 2010a)

The consultation document asked five key questions about the proposal to introduce an autism strategy for Scotland. Of the 170 responses received, the majority were from individuals (114 respondents). Other responses were from: the third sector (33 respondents) and local

authorities (13 respondents), with a further 12 responses from other groups, such as academics, unions and professional bodies (O'Donnell 2010a). The questions and a brief summary of the responses are provided below.

1. **“Would people in Scotland benefit from a National Strategic approach?”** Of the 147 direct responses to this question, the summary of consultation responses states that 96% of respondents (141) ‘unequivocally support’ the introduction of a national strategy. Arguments put forward were that it would “obviate the post-code lottery” in the delivery of services to people with autism across Scotland; it could provide benefits for access to diagnosis and follow up service provision, particularly for those in adulthood; it could improve multi-agency working and understanding of autism.

Four percent of respondents (6) questioned the need for a national autism strategy, with three respondents expressing scepticism about the benefits a national strategy could deliver. One argued that it would be more appropriate to introduce and enforce national standards. Two further respondents argued that a group of individuals with a specific disability should not be singled out as it would disadvantage other groups (O'Donnell, 2010a)

2. **Is a Scottish Autism Strategy Act needed to make a National Autistic Spectrum Disorder Strategy effective?** The summary of consultation responses states that, of the 145 responses to this question, 90% (130) supported the proposal to provide legislative force to a national strategy. Reasons given for support included that: it would provide financial security to the strategy in a tight financial climate; it would ensure multi-agency co-operation; England already has a national autism strategy backed by legislation to ensure compliance and Scotland should not lag behind. Two respondents in support of the introduction of legislation added that, for it to be effective, it would also need to be backed by sufficient funding, staffing and oversight of the strategy (O'Donnell 2010a)

Ten percent of respondents (15) disagreed with the need for introducing legislation for a national autism strategy. Again, it was argued that legislation for supporting individuals with a specific disability could disadvantage other groups, with a few respondents suggesting that it would be contrary to the aims of the [Education \(Additional Support for Learning\) \(Scotland\) Act 2004](#). Two respondents argued that the introduction of legislation in England was not in itself a valid argument for introducing it in Scotland, and that the effectiveness of the English legislation had yet to be assessed (O'Donnell 2010a).

3. **Are the duties proposed appropriate to enabling a National Autistic Spectrum Disorders (ASD) Strategy for Scotland?** Three quarters (103) of the 136 respondents to this question generally supported the statutory duties proposed. However, a number of respondents suggested improvements to the proposed duties and the following observations were made: success of the strategy would be determined by those delivering relevant services; consultation with people on the autistic spectrum was essential to determine appropriate statutory duties; concerns were raised about appropriate funding for implementation; the strategy would need to be effectively monitored and evaluated; the proposed strategy did not mention the criminal justice system or information relating to issues such as social support, employment support or self directed support (O'Donnell 2010a).

Some respondents did not believe that the proposed duties would be appropriate or effective, arguing that the duties were not costed and were too vague to be effective. One respondent argued that there was already a framework in place, and two respondents

argued that the [Education \(Additional Support for Learning\) \(Scotland\) Act 2004](#) supersedes the need for these legislative duties to be introduced.

4. **Are the duties proposed appropriate to guide local agencies to take a strategic approach to autism services in their area?** Sixty eight per cent of the 136 respondents (93) to this question thought that the proposed duties would be appropriate for this purpose. However, concerns were raised over a perceived lack of clarity in relation to the proposed duties, with some arguing for a national implementation group to implement the strategy and others suggesting the need for local leadership and local implementation strategies. Some also considered that a lack of experience and understanding of ASD could undermine the effectiveness of the strategy and that more training would be required amongst professionals, particularly teachers. Again, the issue of sufficient funding and support for delivery of services was raised as a requirement to ensure the effective implementation of the strategy. The difficulties of multi-agency working across differing health and education authority boundaries was also raised (O'Donnell 2010a).

5. **Are there any other comments you wish to make about this proposal?** Ninety two additional comments were received. A significant number of respondents at this point re-emphasised their support for introducing a national autism strategy, backed by legislation, for the following reasons: a strategy was seen as long overdue; it would give people with ASD in Scotland parity with those in the rest of the UK; it would improve understanding and awareness of ASD; and it would ensure comprehensive provision of services to children with ASD.

Several additional comments were made about what would be needed to ensure that a strategy would be effective: Sufficient training would need to be given to service providers, as well as sufficient resource; the strategy should deliver for adults as well as children; access to diagnosis needs to be improved; multi-agency working needs to be effective to make the strategy work. One respondent argued that all children on the autistic spectrum should have an advocate to represent their needs. Another suggested that the proposal should include a greater role for parents. A couple of respondents suggested that the proposed strategy should be widened. One suggested it should incorporate those with cerebral palsy, dyspraxia and communication problems. Another respondent argued that the strategy should cover services to all children with disabilities (O'Donnell 2010a).

Following the consultation, on 26 May 2010 Hugh O'Donnell MSP introduced the [Autism \(Scotland\) Bill \(SP Bill 44\)](#) (plus accompanying documents) in the Scottish Parliament. Each section of the Bill is examined later in this briefing, along with a summary of the written evidence received by the Education, Lifelong Learning and Culture Committee on the general principles of the Bill.

SCOTTISH GOVERNMENT RESPONSE

The Scottish Government say that the work of the [Autistic Spectrum Disorder \(ASD\) Reference Group](#) now needs to be refreshed, and that a national autism strategy could be achieved without legislation (Scottish Government, 2010d). It specifically listed the following ASD related activities that support individuals with ASD: Guidance for professionals, including guidance on commissioning in health and social care, clinical practice guidance, diagnostic standards and the Autism Toolbox for education staff. Training opportunities are available from SVQ level 3 up to Doctorate level. Information and support services include 'one stop shops' in Edinburgh and Glasgow to provide information, training, socialisation and employment coaching to adults

(particularly those with Asperger's), and the Autism Network which can direct people to suitable services.

In addition, the Scottish Government pointed to a number of more general policy initiatives which, though not specifically focused on autism, may be of benefit to people on the autistic spectrum. These include: Getting it Right for Every Child, ['The same as you?'](#) (a strategy running since 2000 aimed at developing services to better meet the needs of the people living with a learning disability and autism spectrum disorder) the development of local authority outcome measures for people with ASD, and improving national data collection and information sharing through the learning disability [e-say](#) project. In 2009, a National Transitions Officer was appointed to support families in transition for child to adult services. There are also education focused policies addressing transition to adult life including 'more choices more chances' and ['16+ Learning Choices'](#) both of which are designed to capture those individuals who are most likely to miss out on further education and training opportunities, including individuals with ASD. The Scottish Government recently published [Caring Together: A Carer's Strategy 2010-2015](#) which aims to improve the identification, assessment and support of carers in Scotland, including provision of support to carers by local authorities and NHS bodies and identification of carers and their needs by professionals (Scottish Government, 2010e). The Scottish Government's [Framework for Supported Employment in Scotland](#) '*A Working Life for All Disabled People*' focuses on supporting individuals who have a disability or a long term health condition who need additional support to get into work (Scottish Government, 2010g).

Finally, the Scottish Government's submission said that they had already committed to publishing a draft 'National Autism Strategy' for consultation by the autumn of 2010. ['Towards an Autism Strategy for Scotland'](#) was issued on 9 September 2010 and the consultation closes on 9 December. Chapters 1 and 2 of the consultation document examine the autistic spectrum and its prevalence, and provide a history of the actions taken under the various existing policies and initiatives outlined in the previous section of this briefing. These activities are grouped under five main headings:

1. diagnosis, assessment and interventions;
2. matching resources to need;
3. standards, monitoring and scrutiny;
4. staff education and training; and
5. research

Chapter 3 outlines the various 'gaps' that currently exist in service provision and sets out the Scottish Government and re-convened ASD reference group's draft strategy in 26 recommendations (listed at Annexe 1), using the five themes listed above. The overarching vision is that:

"All people on the autism spectrum are "respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives." (Scottish Government, 2010a)

EXISTING LEGISLATION

There is currently no legislation in Scotland that specifically relates to autism spectrum conditions. However, there is existing UK and Scottish legislation that would be applicable to the rights and needs of individuals with additional support needs and disabilities, such as those on the autistic spectrum. It should be noted that this list is not exhaustive.

Social Work (Scotland) Act 1968 placed duties upon local councils for the organisation and provision of welfare services for "persons in need". It introduced a duty on local authorities in

Scotland to “promote social welfare” and provided a structure for social work in Scotland (O’Donnell, 2010a).

National Health Service and Community Care Act 1990 requires local authorities to assess the need for “community care services”. It also enhanced their duty to secure the provision of accommodation and other welfare services for the elderly, disabled and individuals suffering from mental/physical health problems.

Education (Disability Strategies and Pupils’ Educational Records) (Scotland) Act 2002 requires education authorities to prepare and implement accessibility strategies to improve access for pupils with disabilities to the curriculum.

Education (Additional Support for Learning)(Scotland) Act 2004 created a broad definition of additional support needs which includes all children, who, for whatever reason, require additional support with their education. A statutory Code of Practice provides further guidance and amending legislation in 2009 requires an advocacy service to be established. The Act places a duty on education authorities to make arrangements to identify those children or young people with additional support needs and to make adequate and efficient provision for the additional support required by children and young people.

Adult Support and Protection (Scotland) Act 2007 provided for new inspection and investigation powers for local authorities and a range of related interventions for adults at risk.

The Equality Act 2010 has changed the definition of disability and extended protection against disability discrimination. The new definition is that:

“A person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities” (UK Government Equalities Office, online)

The UK Government Equalities Office (GEO) consultation on: ['Guidance on matters to be taken into account in determining questions relating to the definition of disability'](#) uses autism as an example of disability to highlight where the new Equalities Act 2010 would be applicable. For example:

“A man has Asperger’s syndrome, a form of autism, and this causes him to have difficulty communicating with people. He finds it hard to understand non-verbal communications such as facial expressions, and non-factual communication such as jokes. He takes everything that is said very literally, and therefore has difficulty in making or keeping friends or developing close relationships. He is given verbal instructions during office banter with his manager, but his ability to understand the instruction is impaired because he is unable to isolate the instruction from the social conversation. [...] It would be reasonable to regard these impairments as having a substantial adverse effect on normal day-to-day activities” (GEO, 2010)

In particular, the Act extends protection against discrimination in relation to goods and services, against discrimination that occurs because of something *connected to* a person’s disability and to indirect discrimination

Service providers and public authorities are required to make changes, where needed, to improve services for disabled customers or potential customers. There is a legal requirement to make reasonable changes to the way things are done (such as changing a policy), to the built environment (such as making changes to the structure of a building to improve access) and to provide auxiliary aids and services (such as providing information in an accessible format or additional staff support when using a service). Under the new Equality Act, adjustments must

be made where disabled people experience a 'substantial disadvantage'. This means that service providers may have to make more adjustments than under the previous legislation.

BILL PROVISIONS AND SUMMARY OF EVIDENCE

There are five sections to the Autism (Scotland) Bill as introduced. Sections 1 and 2 of the Bill provide for a statutory duty to be placed on Scottish Ministers to prepare and publish an autism strategy and to issue guidance to local authorities and NHS bodies on the strategy. Section 3 provides for local authorities and NHS bodies to have a duty to have regard to the guidance produced. Sections 4 and 5 provide for interpretation, short title and commencement.

The [Policy Memorandum](#) and [Bill's explanatory notes](#), whilst acknowledging that legislation and policy initiatives already exist in relation to the Bill's proposals, argue that this existing legislation and policy is not sufficient to ensure the provision of necessary services to individuals with ASD. Several gaps in current provision were identified, in particular with diagnostic services, support in mainstream schooling, the transition from child to adulthood and adult services; and support into employment. It points out that Scotland is now the only part of the UK without a national autism strategy and that, regardless of existing policy and legislation; large gaps in service provision still exist. The Financial Memorandum to the Bill argues that the introduction of a national strategy, underpinned by legislation, would address the discrepancies that currently exist in service provision.

COMMITTEE CALL FOR WRITTEN EVIDENCE

At its meeting on 15 June 2010, the Autism (Scotland) Bill was referred by the Parliamentary Bureau to the Education, Lifelong Learning and Culture Committee (the Committee) for Stage 1 consideration. The Parliament agreed that Stage 1 consideration should be completed by 21 January 2011. The Committee issued a call for evidence on 7 July 2010, seeking views from individuals and organisations on the general principles of the Bill. The call for evidence closed on 8 October 2010 and a total of 140 public submissions were received. Table 4 (below) shows the distribution of responses based on the broad sectoral interests of the organisation or individual.

Table 4: Written evidence received, by respondent group

Respondent Group	Responses
Local Authorities	14
NHS Bodies	3
Professionals/academics	15
Autism Groups and Organisations (including service providers)	24
Voluntary/third sector organisations	8
Individuals, parents and carers	74

The majority of evidence received by the Committee was from individuals with ASD, their parents or carers, and autism groups. In addition, written evidence on the Bill was received from

the Law Society of Scotland and the Equalities and Human Rights Commission (EHRC). The views of these groups and some of the key issues raised are briefly summarised below, with further analysis of the evidence provided under each section of the Bill.

KEY ISSUES RAISED IN SUMMARY OF EVIDENCE

A raft of detailed evidence was provided to the Committee, covering the broad spectrum of issues currently faced by individuals with ASD. Many respondents provided extensive feedback on the effectiveness of existing policies and legislation and highlighted specific examples of good practice, as well as identifying gaps. Whilst this briefing does not explore these issues in detail, some of the key points raised by various respondent groups are provided below:

- It was acknowledged across respondent groups that more detailed research is required, in particular to identify the population with ASD and to map/assess the needs of those individuals on a national basis. The variability of the extent to which these conditions affect people's lives means that the level of support required by individuals also varies significantly. Assessment needs to be individual needs-led, making mapping, assessment and planning of service provision for individuals with ASD, at a national level, very complex
- A definition of ASD should be included in legislation in order to ensure that all those who fall within the autistic spectrum would be provided for. Continuous developments in understanding and classification of disorders on the spectrum raise issues for providing a statutory definition
- Whilst some good examples of existing support were identified, several gaps in service provision, specific to meeting the needs of individuals with ASD were raised, including: access to diagnosis, early intervention programmes, transition support from childhood to adult services, employment services for adults with ASD, advocacy services, support in the criminal justice system, leisure and transport
- Training of professionals is crucial to increasing understanding and awareness of disorders on the autistic spectrum. This would, in particular, contribute to earlier diagnosis and more effective interventions
- Many of the individuals, families and carers, as well as autism groups, said that individuals with ASD could contribute greatly to the economy and society, if provided with the correct support. As long as gaps in support exist, this opportunity is being lost
- The prospect of a national autism strategy was generally welcomed as a means of providing a cohesive approach and of encouraging better multi-agency working. However, there was less agreement between respondent groups on the need for legislation to underpin such a strategy

BILL PROVISIONS

Section 1 - An Autism Strategy

Section 1 of the Bill provides that Scottish Ministers should 'set out a strategy for meeting the needs of persons in Scotland with autistic spectrum conditions by improving the provision of 'relevant services' to such persons by local authorities and NHS bodies'. It is not, however, prescriptive about the contents of such a strategy. Section 1(3) provides for the strategy to be published no later than four months after the Bill comes into force. Sections 1(4) and 1(5) provide for a duty to be placed on Scottish Ministers to 'keep the strategy under review' and if

revised, to publish the revised version. Neither is the Bill prescriptive about how often the autism strategy should be reviewed. Section 1(6) provides for a duty to be placed on Scottish Ministers to consult with 'appropriate stakeholders' in preparing an autism strategy, and before revising the resulting strategy at any time thereafter.

Summary of Written Evidence

There was a general sense of agreement across all respondent groups that the introduction of a national autism strategy would be welcomed, as a means of co-ordinating the various existing initiatives and policies and to provide a joined-up strategic approach to diagnosis and service provision for individuals with ASD.

Evidence from individuals with ASD, parents and carers, as well as all of the autism groups and organisations representing them, continually referred to inconsistent service provision across local authority areas, arguing that a national strategy would help to alleviate this problem. Some also stated that the introduction of a national strategy would bring Scotland into line with the rest of the UK. In its written evidence to the Committee, the Scottish Society for Autism stated:

“There can be no doubt that people with autism in Scotland would benefit from a national strategic approach. There are significant variations in the provision of care, often based on affordability, which leads to the perhaps clichéd but in this case appropriate term “postcode lottery”. There are bottlenecks in diagnosis, unaddressed diagnoses and discontinuities in care, due to short-term contracts based around local authority spending plans” (Scottish Society for Autism)

Autism Initiatives Scotland (a provider of direct support to people with ASD and their families) agreed, suggesting that, comparatively, Scotland was fairly advanced, but that gaps in knowledge and service provision remain:

“We are involved in a variety of autism strategy groups across Scotland and also we have an international presence through our links with Autism Europe and the World Autism Alliance. In these forums, it is evident that understanding and range of support to people with autism in the UK, and particularly in Scotland, is as advanced as anywhere else. However, in Scotland, significant gaps still exist, particularly in ensuring that good practice is understood and shared. Legislation could provide a framework for ensuring that good practice is embedded in service provision across Scotland” (Autism Initiatives Scotland)

All of the autism groups and organisations involved in the consultation were, in general, supportive of the proposal for legislation to underpin a national strategy, believing legislative force would help support delivery of the strategy in a consistent manner. This argument was supported by the vast majority of individuals, parents and carers, as well as all other voluntary/third sector organisations. However, some respondents observed that legislation would only be worthwhile if it could be effectively enforced, and if it was backed by sufficient resources.

Local authorities expressed concern that such legislation might lead to unfairness in the distribution of resources amongst disability groups. In its written evidence COSLA said:

“COSLA has a fundamental concern with the principle of delivering a national autism strategy by means of legislation and, as such, we are not supportive of the Autism (Scotland) Bill. We believe that placing a specific autism strategy in statute risks distributing resources inequitably, and without necessarily building a sustainable and strategic longer term solution that addresses the needs of people affected by autism. In our view, the risk is that the Bill could lead to resources and activity being governed by a

narrow set of statutory processes, rather than being directed according to the delivery of improved outcomes. This could lead to particular difficulties for councils in the context of budgets that are already stretched and there is a fear that money could end up being directed away from other support services and that any benefits for people with ASD could be at the expense of people with other disabilities.” (COSLA)

Similar concerns were raised by other respondents, including the Association of Scottish Principal Educational Psychologists (ASPEP) and the Equalities and Human Rights Commission (EHRC), that the introduction of specific legislation for individuals with ASD could create preferential treatment for certain conditions or disabilities:

“Any legislation introduced to address the needs of a specifically identified group, in this case those identified as being on the autism spectrum, is potentially discriminatory; it runs the risk of highlighting the needs of one group of individuals over other groups who also have additional support needs. An outcome of such legislation would be to divert scarce resources away from other groups with additional support needs towards those identified as being on the autism spectrum.” (ASPEP)

“Whilst it is important that treatment is appropriate for the individual and their specific impairment, it may not be helpful to statutorily separate one impairment type from another. Not only does this have practical difficulties from a resourcing point of view but it also may not be appropriate for a number of people who will have more than one impairment type. We would also suggest that whilst there are significant differences between impairments and the lived experience of people with different impairment types, there are similarities in the attitudinal and social barriers which prevent the required step-change to improve service delivery. The work of the Independent Living in Scotland project is focusing on bringing disabled people together, regardless of impairment, to voice their demands for equality and the right to control their own lives through making their own choices.” (EHRC)

However, many of the individuals’ and autism groups’ evidence argued that autism is a ‘hidden disability’ that is not always recognised, and that the introduction of a national strategy with underpinning legislation would raise awareness and help society to better understand the diverse needs of individuals with ASD.

Section 2 - Guidance and Consultation

Section 2(1) of the Bill provides for a duty to be placed on Scottish Ministers to issue guidance to local authorities and NHS bodies on the implementation of the resulting ‘autism strategy’, in relation to their provision of “relevant services” (as defined by section 4 of the Bill). As with section 1(1), section 2(6) of the Bill places a duty on Scottish Ministers to consult with ‘appropriate stakeholders’ before issuing, or substantially revising, any guidance prescribed under section 2.

Section 2(5) provides for this guidance to cover the following:

- “relevant services” for diagnosing ASD
- identification of persons on the spectrum
- needs assessment of persons with ASD for “relevant services”
- planning in relation to provision of “relevant services” for the transition from childhood to adult life
- other planning in relation to the provision of “relevant services” to people with ASD
- Training of staff who provide “relevant services” to people with ASD
- local leadership arrangements in relation to the provision of “relevant services”

The [Bill's explanatory notes](#) state that the list of issues to be covered in the guidance is not exhaustive and that “Scottish Ministers are free to include other matters, other than those provided for in the Bill.

Section 2(3) of the Bill places a duty on Scottish Ministers to keep the guidance under review and provides the power to revise it. As with section 1(4) relating to review of an ‘autism strategy’, section 2(3) of the Bill does not prescribe how often the guidance should be reviewed. However, unlike section 1(5) which requires the autism strategy to be published whenever it is revised, there is no requirement placed on Scottish Ministers to publish revised guidance on service provision.

Section 2(4) provides that, when reviewing the guidance, Scottish Ministers should have consideration as to the ‘effectiveness’ of the guidance in securing the implementation of the resulting ‘autism strategy’. It does not say how effectiveness, in this respect, is to be assessed.

Summary of Written Evidence

Evidence provided by individuals, parents and carers, autism groups and organisations suggests that the key gaps in the necessary services available for individuals with ASD are related, in particular, to access to diagnosis and the transition from childhood to adult services. Many commented that, whilst policy and legislation exists to support children with additional support needs, this support is not consistent across the country and indeed becomes more variable when considering adult services for individuals with ASD. Evidence provided by the National Autistic Society Scotland (NASS) said:

“Our research suggests that almost a third of adults with autism have developed severe mental health problems, as a result of a lack of support. It suggests that many undiagnosed adults with autism are experiencing difficulty with regard to criminal justice, housing, unemployment and deteriorating mental health” (NASS)

The Scottish Society for Autism (SSA) said:

“We also must address the division between children and adult services. This division has several important elements of which the first is legal status. Children with an autistic spectrum disorder (ASD) have a legal right to an education, and the state is obliged to provide such. The situation for adults is much weaker, with a plethora of policies in place which are followed to a greater or lesser degree according to local politics and expediency” (SSA)

In addition, the importance of the training of professionals involved in the diagnosis, assessment of need and provision of various services was raised. Many of the individual respondents and their families/carers felt that key to maximising the long term outcomes for individuals with ASD was being able to access the right services at the right time, generally through early intervention, for which diagnosis is crucial. The written evidence suggests that understanding and knowledge of conditions on the autistic spectrum is variable and inconsistent, and that improved training for professionals would help in improving early diagnosis.

A series of suggestions were made by respondents across the various groups about what specifically should be covered in the guidance, with particular attention paid to the criminal justice system, employment services, independent living, leisure and transport. It was widely acknowledged throughout the written evidence that consultation on the detail of guidance would be necessary and appropriate.

In contrast, many local authorities considered that there was already adequate guidance and duties in place, through legislation such as the Additional Support for Learning (Scotland) Acts 2004 and 2009, and strategies such as “Getting it Right for Every Child (GIRFEC).

Commencement and Timing

Section 2(2) of the Bill requires the guidance to be issued by Scottish Ministers within 12 months of the Bill coming into force. As the Bill would come into force two months after receiving Royal Assent (provided for in Section 5(2)), and Section 1(3) provides for the Strategy to be published within four months of the Bill coming into force, this would mean that an autism strategy would need to be published within six months of Royal Assent, and guidance would need to be issued no later than six months from this date.

In its written submission, the SSA suggested that the timeframe in which this legislation was to be achieved could be detrimental to the development of a coherent national strategy and that, whilst it is committed to development of a national strategy, legislation could be introduced at a later date when the details of the strategy have been finalised and agreed.

Section 3 - Duty on Local Authorities and NHS Bodies

Section 3 of the Bill places a duty on local authorities and NHS bodies ‘to have regard to’ the specified guidance issued under section 2 of the Bill when exercising their functions in relation to their provision of ‘relevant services’. The legislative implications for local authorities and NHS bodies of this “duty to have regard to” guidance issued under an ‘autism strategy’ are explained in Box 1 below.

Summary of Written Evidence

While the vast majority of individual respondents, their families and carers, autism groups and other voluntary organisations, welcomed the proposed introduction of guidance for local authorities and NHS bodies, concerns were raised on the statutory implications of the Bill as introduced:

“Having regard to the guidance must be worded so that local authorities do have to take regard of the guidance, as unless this wording is considered properly, then local authorities may be able to say one thing and do another” (National Autistic Society – Perth Branch)

“Our primary concern is that this Bill could be passed, and the Government could fulfil its duties, without any difference being made to the lives of people with ASD. The majority of the services that need to be improved for people with ASD are not the direct responsibility of central government; they are devolved to health boards and local authorities. Although section 3 of the Bill includes a duty on these bodies to “have due regard” to the guidance issued by the Government under Section 2, the concordat between central and local government in Scotland means that local authorities are under no obligation to implement the strategy, or to produce their own” (Turning Point Scotland)

Section 4 - “Appropriate Stakeholders” and “Relevant Services”

Section 4 provides definitions of the terms used in the Bill. In section 4(1), ‘relevant services’ are defined as health services provided by NHS bodies (defined in Section 4(1) to be health boards, special health boards and the Common Services Agency as provided for in the [National Health Service \(Scotland\) Act 1978](#) (the 1978 Act)), and local authority services related to the assessment, care and support of persons with autism. ‘Relevant services’ is interpreted in Section 4(2) to include: ‘arranging provision of relevant services’.

Section 4(1) prescribes 'appropriate stakeholders' as:

1. organisations representing people with ASD
2. organisations representing professionals who deliver support to people with ASD
3. organisations involved in research relating to services provided to people with ASD
4. Local authorities
5. NHS Bodies

These stakeholders will need to be consulted on a draft autism strategy, on the contents of the guidance issued relating to the strategy, and before any revisions of either the strategy or guidance, if substantial, after the Strategy's introduction.

No definition of autistic spectrum conditions is provided in the Bill. The [Bill's explanatory notes](#) say that placing a statutory definition of ASD into legislation would not provide sufficient flexibility for further developments and understanding of the spectrum.

Summary of Written Evidence

The Academy of Medical Royal Colleges and Faculties in Scotland (representing members from the Royal College of Radiologists, the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health, Royal College of General Practitioners) commented on the terminology in the Bill, stating that the term 'Autistic Spectrum Disorder' should be used to accurately reflect all those on the autistic spectrum. This opinion was backed by several other respondents, across respondent groups. NHS Ayrshire and Arran commented that:

"If the intention of the Bill is to recognise individuals with autism as a vulnerable group, and act to safeguard support for their very specific needs, the use of an appropriate definition of autism is important (as detailed in the triad of impairment defined by Lorna Wing, 1981), which recognises the specific, and invisible, vulnerabilities of this group" (NHS Ayrshire and Arran)

Some concerns were raised by various respondents about the definition of 'appropriate stakeholders' and 'relevant services' in section 4 of the Bill. Suggestions were made that 'appropriate stakeholders' should include:

- 'organisations representing individuals with ASD and their families',
- 'organisations representing carers',
- 'organisations representing advocates',
- 'voluntary sector service providers' and
- 'employment service providers'

Suggestions for additions to the definition of 'relevant services' included: employment, training, education, transport, advocacy and leisure.

Box 1: Statutory Interpretation of “Duty to have Regard to”

Phrases in any statute are interpreted according to the rules of statutory interpretation which have been developed by the courts. The courts have previously found that the nature of the duty imposed on a person who must “have regard to” something is that they must take it into account when exercising their functions under the statute in question. However, the words impose no duty of obedience such that the person has to comply. For example, in the English case of *The Governing Body of the London Oratory School v the Schools Adjudicator* (No 1) [2004] EWHC 3014, the judge held, at paragraph 40:

“The phrase ‘to have regard to’ means take into account. It does not connote slavish obedience or deference on every occasion. It is perfectly possible to have regard to a provision but not to follow that provision in a particular situation.”

Judicial review is the main type of court action that is used by individuals and organisations to challenge the exercise of statutory functions by public authorities. Accordingly, authorities exercising statutory functions will have regard to the principles developed by the courts, in the context of judicial review actions when exercising these functions. These principles include the requirement on such authorities to take into account relevant considerations (such as those which they are directed by a particular statute to have regard to) and to not take into account any irrelevant considerations. Whilst there is not a general duty to give reasons for administrative decisions, if a body decides that something they are directed to have regard to by a statute should not be followed because it is outweighed by another relevant consideration, the advice given to them is to ensure that their reasoning for doing so is explicit and well-documented. Failure to do so may leave them vulnerable to an action for judicial review (Harvey-Clark, 2010)

The Bill’s explanatory notes make it clear that the Bill does not prescribe how local authorities or health bodies should implement any guidance produced under this legislation. In practice therefore, **the provisions in Section 3 of the Autism (Scotland) Bill as introduced would mean local authorities and health boards cannot ignore the guidance issued by Ministers on an Autism Strategy, but “having a duty to have regard to” does not mean that they have to comply with the guidance, if they have other reasonable considerations to take into account.** This could mean in practice that guidance issued will be considered, but may not be followed if local authorities or NHS bodies took for example, lack of available resources or services for other groups, into account when providing “relevant services” for individuals with ASD under the “Autism Strategy” guidance.

The advice given to public authorities in Scotland on decision-making in accordance with the principles associated with judicial review can be found in the Scottish Government’s (2010c) [Right First Time: A Practical Guide for Public authorities in Scotland to Decision-Making and the Law](#). A general introduction to court actions for judicial review can be found in the SPICe Briefing entitled [Judicial Review](#) (Harvie-Clark, 2009).

FINANCIAL IMPLICATIONS OF THE BILL

The [Bill's Financial Memorandum](#) (FM) places the cost of the Bill at 'no more than £5,000' for the Scottish Government to prepare, consult on, and publish an autism strategy; and approximately £1,500 per local authority or NHS body to respond to the autism strategy consultation. The Bill refers only to the financial implications of the process of developing a strategy and guidance, and does not infer any costs relating to the implementation of such a strategy or guidance. The FM states:

“The Bill does not dictate the content of the strategy at all and, while it gives some guidance as to the matters which should be covered in the guidance, it does not specify in what way the substance of those matters should be addressed. The contents of the strategy and the guidance will be determined by the Scottish Ministers after consultation. Until the contents of these documents are known, it is obviously impossible to estimate the costs which local authorities and NHS bodies will incur in having regard to the strategy and the guidance in exercising the relevant functions. To that extent, the costs of implementation are not directly attributable to the Bill, but to the completed strategy and guidance and to the extent to which the guidance is followed by local authorities and NHS bodies” (SP Bill 44, Financial Memorandum)

The costs to individuals, businesses and other bodies of responding to an autism strategy consultation are estimated in the FM as approximately £10 and £100 per response, respectively.

Savings

Although the FM does not estimate the costs to local authorities or health board of implementing the Bill's provisions, it does refer to the potential savings that could be made as a result of implementation. A recent report from the [National Audit Office](#) (NAO) in 2009 quotes a recent study by researchers at King's College London (Knapp, M. et al, 2007) which estimated that:

“Autism costs the UK economy around £28.2 billion per year (£25.5 billion for adults, and £2.7 billion for children). Of the £25.5 billion cost for adults, 59% is accounted for by services, 36% by lost employment for the individual with autism, and the remainder by family expenses)” (NAO, 2009)

The FM to the Bill states that the NAO has identified the true cost of autism services and support in Scotland as approximately £2.3 billion per annum. It goes on to explain that significant savings could be made if the correct care and support was provided to individuals with ASD at the right time. Not only would savings accrue to individuals, but the costs to government, local authorities and NHS Bodies would also fall. For example, the implementation of co-ordinated early intervention programmes may reduce the reliance on more expensive care packages and, therefore, reduce the cost of support to individuals with ASD in the longer term. There would also be financial benefits to the economy of providing the appropriate support, as it may enable individuals with ASD to achieve better individual outcomes more quickly, and to contribute to the economy through employment and development of skills.

Scottish Government Position on the Financial Implications of the Bill

The Scottish Government's [written submission to the Scottish Parliament's Education, Lifelong Learning and Culture Committee](#) (18 June 2010) states that no specific research has been carried out into the true cost of ASD in Scotland. It also argues that the costs associated with implementing the Bill should be considered in relation to the potential savings attributable to the

introduction of the Bill, as identified in the Bill's Financial Memorandum. The Scottish Government highlights the concerns raised by the [Convention of Scottish Local Authorities \(COSLA\)](#) that, if the true costs of implementing the legislation and guidance are not identified, the introduction of such legislation could result in resources being directed away from other support services in order to provide the 'relevant services' for people with ASD, suggesting that those individuals with ASD would be provided for at the expense of individuals with other disabilities. The Scottish Government's submission concludes that it does not accept that the Bill will have minimal financial impact upon local authorities (Scottish Government, 2010d).

Summary of Written Evidence

Many of the individuals, parents, carers and autism groups highlighted the costs of meeting the needs of individuals with ASD and the impact that this can have on their everyday lives. It was suggested in several submissions, across respondent groups, that similar research to that undertaken in England by the National Audit Office should be carried out in Scotland to identify the true costs of services for those with ASD.

Many consultation respondents also pointed out the need for additional resources to back up the introduction of a national strategy, in order for it to be effective. Local authorities in particular raised concerns about the redirection of resources away from others in need of additional support.

ANNEXE 1: LIST OF MAIN RECOMMENDATIONS IN THE SCOTTISH GOVERNMENT'S DRAFT AUTISM STRATEGY

1. The ASD Reference Group should be reconvened on a long-term basis, including CoSLA membership, to oversee developments of the resulting autism strategy and to progress change. It should produce an annual report to relevant Ministers.
2. The work of Knapp et Al (2007) on the economic costs of autism should be analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole.
3. The ASD Reference Group should explore options for developing user and carer capacity to be able to participate in local planning processes.
4. The ASD Reference Group should commission research to examine and compare the outcomes in relation to quality of life, for those who are supported by autism service providers and individuals who access generic provision. The findings should be used to inform revised guidance for commissioners of services for people with ASD.
5. The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan.
6. Existing reports on the work of the [Scottish Autism Services Network](#) should be formally evaluated with a view to assessing its long-term viability and effectiveness.
7. The ASD Reference Group should contribute to a review of the SIGN guidelines and in doing so, consider where and how best this innovation might be replicated for adults and other relevant professions.
8. A request should be made to [NHS Quality Improvement Scotland](#) as the body into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults.
9. Approaches will be made to the [Royal College of Physicians and Surgeons](#) to establish the feasibility and desirability of disseminating ASD materials in e-CPD formats.
10. An assessment of national waiting lists should be undertaken to clarify the extent of delays and the ASD Reference Group will consider and respond to these findings.
11. Initiatives to address waiting lists for assessment should include consideration of further training on the use of ADOS, ADI-R, 3di and DISCO to meet increased levels of demand.
12. The ASD Reference Group will explore the ways in which diagnostic processes for adults and children are different and how this should inform practice.
13. The directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed.
14. Agencies and services should develop a menu of interventions including therapeutic interventions and counselling for children, young people and adults with an ASD that are immediately available, appropriate and flexible to individual need.

15. Consideration should be given to the specific supports needed for the more able individuals with ASD
16. The effectiveness of implementation of the Commissioning guidance should be reviewed by the ASD Reference Group by facilitating an audit of current service commissioning.
17. It is recommended that the ASD Reference Group hosts an event to evaluate and recognise good practice in Scotland to disseminate models of practice, to evaluate success, recognise benefits and limitations and agree how to develop good models across the country in a way that is cost-effective.
18. The ASD Reference Group will explore the benefits of ASD lead officers, with the Association of Directors of Social Work and with COSLA, to establish how rollout across Scotland might best be achieved.
19. The [Self Directed Support Strategy \(SDS\) Implementation Group](#) and the SDS Bill Reference Group should ensure representation from the autism community so that their interests are taken into account as further developments take place.
20. The [Framework for Supported Employment in Scotland](#) should be evaluated in terms of its impact on employment and employability for people with autism.
21. A review should be conducted with a view to updating and re-distributing the quality diagnostic standard if it is found to continue to be of benefit.
22. the ASD Reference Group should meet with representatives of both [Social Care and Social Work Improvement Scotland](#) (SCSWIS) and [Health Improvement Scotland](#) (HIS) as well as other relevant regulatory bodies, such as those in education and criminal justice, with a view to learning about current developments and ensure that the needs and wishes of those on the spectrum are taking into account in future programmes.
23. The ASD Reference Group should work collaboratively, and offer support, to CoSLA, NHS, criminal justice and other relevant public bodies to offer support to local authorities to effect the implementation of the various autism guidelines.
24. The Training Sub-Group of the main ASD Reference Group should be reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer.
25. An evaluation of existing research will be commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers.
26. Good practice transition guidance should be developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions

(Scottish Government, 2010a)

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