#### SUBMISSION FROM THE SCOTTISH GOVERNMENT

## Introduction

1. This memorandum has been prepared by the Scottish Government to assist consideration by the Education, Lifelong Learning and Culture Committee of the Autism (Scotland) Bill, which was introduced by Hugh O'Donnell MSP on 26 May 2010.

# **Background**

- 2. The aim of the Bill is for Scottish Ministers to publish a strategy as the vehicle to meet the needs of people in Scotland with autism spectrum disorder (ASD), principally by improving local authority and NHS provision. It emphasises the importance of Scottish Ministers actively consulting with all those with an interest when preparing or revising the content and stresses the need for regular review to ensure that it remains relevant.
- 3. A key component is the issuing of guidance to local authorities and NHS bodies within a year of statute coming into force which is targeted at identifying individuals with the condition, improving diagnosis and assessment, encouraging better planning (especially in managing the transition from children to adult services) and enhancing staff training and strong local leadership.

#### Consultation

- 4. Mr O'Donnell's consultation exercise ran from early January 2010 until the end of March. It posed five questions about the need for a strategy, its potential benefits, whether statute was necessary, whether the proposed coverage was appropriate and concluded by offering respondents the opportunity to make any additional observations or suggestions.
- 5. A total of 170 responses were received, the bulk of which were from individuals who are on the spectrum themselves or who support someone who is. The detailed breakdown was as follows—
  - 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

6. Eighty seven percent of returns were supportive, 11% opposed the proposals and a further 2% expressed no firm opinion either way. Supporters indicated that a strategy could lead to better access to diagnosis and would be a means to get more nationwide consistency as well as having the potential to improve understanding of the condition and the capacity to develop better joint working. Some opponents questioned the need to legislate for a strategy, whilst others challenged the appropriateness of having statute that could advantage those with autism rather than any other disability. They also indicated that the proposals could conflict with the provisions within the Education (Additional Support for Learning) (Scotland) Act 2004.

#### **Scottish Government's Position**

- 7. An ASD Reference group, consisting of users, carers and professionals established in 2002, 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. This represented Scotland's equivalent of a national strategy and was internationally acclaimed for its innovative approaches but now needs to be refreshed and revitalised to address increasing public expectations.
- 8. The Government, therefore, believes that a revised strategy can be delivered without resorting to legislation to underpin it. The structures and the will to deliver are already there and delivery could begin in the autumn which is some months earlier than awaiting the outcome of Parliamentary passage.
- 9. The Government has committed to the strategy being published by this autumn following a period of public consultation. A near final draft is being considered by the recently re-convened Reference Group on 7<sup>th</sup> June with a view to refining it further. The membership has also been extended to include a COSLA representative to assist partnership working under the terms of the Concordat.
- 10. The Cabinet Secretary for Health and Wellbeing has written Mr O'Donnell advising him of the Government's position and has offered him an opportunity to present his views to the ASD Reference Group on what the strategy should contain.
- 11. Many of the specific issues that the Private Members Bill seeks to address are already being delivered either through the responses made to the original PHIS Report or by other broader Government initiatives. Those that remain will be covered in the strategy itself.
- 12. In addressing the PHIS Report recommendations, funding totalling £4 million was used for a range of programmes including—

- The publication of Commissioning Guidance for health and social care staff who work with people on the spectrum.
- Creating a set of diagnostic standards and a directory of diagnosticians as well as reducing the number of instruments used across Scotland in order to improve the consistency of diagnosis.
- The establishment of two one stop shops in Edinburgh and Glasgow to provide information, training, socialisation and employment coaching to adults (particularly those with Asperger's).
- Extensive development of education and training opportunities through support given to what became the National Centre for Autism Studies at Strathclyde University, from certificate course through to Doctorates. This was then supplemented by creating vocational qualifications at levels 3 and 4 on autism through development work undertaken in conjunction with the Scottish Social Services Council to boost the numbers of front-line staff that had specialist expertise.
- The creation of a Scottish autism network to act as a national hub to direct people to suitable services.
- 13. As well as the work of the ASD reference group, a wider agenda of Scottish Government legislation and policy initiatives addresses, or will address, the needs of children, young people and adults with autism. Curriculum for Excellence prepares children and young people for the challenges of life in the 21<sup>st</sup> century. It builds on the strengths of Scotland's education system. It will raise standards for every child. It will enable every child to become a successful learner, confident individual, effective contributor and responsible citizen. It is a curriculum for all wherever learning is taking place.
- The Government recognises that some children and young people will need additional support to enable them to make the most of their The Education (Additional Support for educational opportunities. Learning) (Scotland) Act 2004 which has been strengthened and updated through the Education (Additional Support for Learning) (Scotland) Act 2009 provides the legal framework which underpins the system for identifying and addressing the additional support needs of children and young people who face barriers to learning. The legislation is based on the idea of additional support needs. This broad and inclusive term applies to children or young people who, for whatever reason, require additional support, long or short term, to help them to make the most of their education. It focuses on the support that children and young people need rather than the diagnosis. Introducing specific legislation around autism would cut across this approach and risk establishing a hierarchy with resultant pressure from other lobby groups, around for example dyslexia, for similar legislation.

- 15. There are also other policies that are either developed or developing that should also have a positive impact on the quality of life for those on the spectrum. These range from the 10 year programme, *The same as you?*, which has addressed the health, social care, housing and social inclusion needs of those with a learning disability and those with autism to the self-directed support strategy itself as well as the ongoing work of the Independent Living Taskforce.
- 16. Beyond this, there is the development of local authority outcome measures for people with ASD as well as improving the collection of statistical data with the new e-SAY data project. The creation of local area coordinator posts across Scotland has also provided many individuals and families with knowledgeable and reliable staff to support them. At national level, a Transitions Development Officer was appointed in April 2009 to ease the passage from children's to adult services. Another significant education resource has been the production of the Autism Toolkit. All in all, these steps demonstrate not only the Government's ongoing commitment to improvement of mainstream and specialist services but the breadth and depth of the work that has been undertaken.
- 17. Scottish Government's overarching approach to work with all children and young people, *Getting it right for every child*, also focuses on improving outcomes for children, concentrating on the individual needs and well-being of the child and seeking to build an appropriate response to these needs. We are also directly funding a wide range of organisations that provide support to families with disabled children (amounting to more than £3.3m in the current financial year), and working closely with the children's disability sector in the For Scotland's Disabled Children Liaison Project on a broad programme of positive action.

# **Financial Impact**

- 18. The Policy Memorandum accompanying the Bill suggests that there will be a minimum, if any, direct impact on local government and health boards and that the financial and resource implications for local government and health boards will be minimal. The member argues that as the Bill does not state what or how the strategy and guidance is to be, then the cost of delivering the guidance is not a cost that arises from the Bill itself (although he does stipulate the range of matters that should be included in the guidance). The costs are attached to the detail of the strategy.
- 19. Although the direct costs from the Bill are limited to the consultation and publishing of guidance it is our understanding that we are also required to consider the costs that emerge from the implementation of a Bill. Mr O'Donnell has pointed out the significant savings that can be made from the development of a strategy emerging from the Bill so it makes sense to balance this with the costs that would be incurred from a strategy that

comes from the Bill. The Bill requires that guidance is issued to local authorities and health boards with specific requirements around the planning of services, training of staff who provide relevant services and provision of services. All of which will come at a cost.

- 20. There has been no specific research conducted into the costs of autism services in Scotland alone. What does exist is the National Audit Office (NAO) report published in May 2009 which gives a recent Kings College London cost of £28.2 billion across the United Kingdom. The Bill itself gives an approximate cost of £2.3 billion for Scotland, based on the NAO report, of autism services. The NAO report indicates that putting investment into supporting 4% of people with high functioning autism will, over time, become cost neutral.
- 21. COSLA, in its submission to Mr O'Donnell's consultation, picks up both these points. They say: 'Public finances are facing significant pressure over the coming years and we are concerned that the imposition of a statutory obligation on local authorities without committed resource could lead to further difficulties within already stretched budgets that impact on overall service provision. If the identified strategy can deliver on the proposal to be cost neutral - meeting the needs of just 4% of adults with ASD will result in a cost saving that will meet the needs of the additional expense required - this would reduce some of the concern about people with autism people treated separately from those with other disabilities. If this is not able to be achieved, then the likelihood is that money will be directed away from other support services and the benefits for people with ASD will be at the expense of other services. There are therefore real concerns that following the proposals may provide a national strategy for one group of people, but detract from the support services able to be provided for others. Without the identification of appropriate resource, at least in the shape of some development or change funding, it is unlikely that the strategy will have the effect intended.'
- 22. In order to understand the financial impacts more comprehensively, the draft strategy includes the following recommendation—
  - "It is recommended that Knapp's work on the economic costs of autism is 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. Particular attention should be paid to his invest to save assertion that if 4% of those with Asperger's were given appropriate support into work this would ultimately mean that those individuals may not require services and could contribute to the economy."

## Conclusion

23. Scottish Government is persuaded for the need to refresh the work that has already been undertaken on autism. However, we do not believe

that legislation is necessary to achieve this. A draft strategy has been written and is likely to go to public consultation in the very near future and would deliver the objectives of the Bill that have not been fulfilled. It is envisaged that the strategy would be published in a final format by this autumn.

24. We do not accept the view that there will be minimal impact upon local government and would want to work in partnership with COSLA in scoping costs and in continuing to develop good quality support for those on the spectrum.

Adult Care and Support Division Primary and Community Directorate 18 June 2010