SUMMARY OF CONSULTATION RESPONSES

SCOTTISH AUTISM STRATEGY BILL

Introduction

The purpose of the draft proposal is to improve support for both adults and children with autism by requiring the Scottish Government to produce a national autism strategy.

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.

The consultation document was made available from a link on the Proposals for Members’ Bills web pages on the Scottish Parliament website. There was also a link to the consultation on the Member’s website.

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.

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

Respondents to the consultation document were invited to answer the five questions contained in it.

Analysis of Responses

General

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.
In addition, a petition initiated by the National Autistic Society in support of the proposal was signed by 482 people.

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.

As noted above, 19 respondents opposed the proposal and 4 neither supported nor opposed the proposal. Amongst those not supporting the proposal, some believed that there was merit in the strategy, but it did not need to be supported by legislation while others rejected the proposal in its entirety. The latter group believed that singling out one group of people with a disability would disadvantage other groups of people with disabilities and was contrary to the aims of the Education (Additional Support for Learning) (Scotland) Act 2004.

In general, however, there was strong support for the measures the Scottish Autism Strategy Bill proposes, particularly amongst those with an autism spectrum disorder and those who care for a person with such a disorder.

Questions

The consultation document posed five questions. The majority of the 163 responses were focussed around these questions. The questions and the responses to them are considered in turn below.
Q1. Would people with autism in Scotland benefit from a national strategic approach?

The terms of the proposal would place a statutory duty on the Scottish Government to prepare and publish a strategy to meet the needs of children and adults with autism across Scotland.

Respondents were asked whether such a national strategy would deliver benefits to people with autism.

There were 147 responses to the question. 141 of the respondents were unequivocal in their support for a national strategy.

Amongst those expressing support for the proposal, a number also highlighted the ways in which it would benefit people with autism. In particular 21 respondents welcomed the strategy on the basis that it would obviate the so-called “post-code lottery”, ensuring consistency in the delivery of services to people with autism across Scotland.

The remaining respondents welcoming the proposal, did so on the grounds that it could provide benefits in terms of improving access to diagnosis and the provision of service after diagnosis in particular for those in adulthood. In terms of improving the service provided, it was contended that this strategy could affect improved multi-agency working and understanding of autism.

One further respondent stressed the benefits that would accrue for the wider society from greater understanding and service provision to people with autism thereby enabling them to provide a meaningful contribution to society.

Six respondents questioned the need for a national strategy. Of these, two respondents expressed some scepticism about the potential for the strategy to deliver perceptible benefits, but did not dismiss the strategy outright. Two argued that it was inappropriate to single out one group of people with a disability for specialist treatment and that it would as a consequence disadvantage other groups. One respondent believed that it would be more appropriate to establish national standards and enforce them, than produce a strategy and one respondent highlighted the reference to “appropriate organisations” to be consulted and questioned whether this perceived vagueness may undermine the Bill’s effectiveness.

Overall, however, there was strong support for the strategy and sense that it could effect significant improvements in the service delivered to people with an autistic spectrum disorder and their families.
Q2. Is a Scottish Autism Strategy Act needed to make a national ASD strategy effective?

The purpose of the proposed bill is to provide legislative force to the national strategy. The consultation document asked consultees whether legislation was necessary to make a national strategy effective.

Respondents were strongly in favour of legislation with 130 of the 145 responses to the question supporting the proposal.

Amongst those expressing support for legislation a number argued why it was necessary. Six respondents noted that it was vital in the current financial climate that the strategy was given the financial security that legislation would provide. Three respondents argued that legislation was necessary to ensure multi-agency working and cooperation.

Five respondents noted that legislation is already in place in England to ensure the preparation of and compliance with a national strategy and not to do so would leave Scotland lagging behind. One respondent argued that the consultation required by the Bill to inform the strategy would mean that resources were better directed and more cost effective.

Two respondents in supporting the need for legislation argued that for it to be effective there needed to be proper funding, staffing and oversight of the strategy.

15 respondents argued that there was no need for legislation. Three respondents contended that providing legislation to support services to people on the autistic spectrum would necessarily disadvantage other groups of people with a disability. Three further respondents also argued that it was inappropriate to single out a specific disability group, contending that to do so would be contrary to the aims of the Education (Additional Support for Learning) (Scotland) Act 2004. Two respondents expressed the view that legislation was not the way forward with greater focus required on the services who will deliver support to people with autism under the strategy. Two other respondents contended that legislation was only being considered because it had been enacted in England and this in itself was not a good enough reason for legislation. Furthermore, they noted that it was not yet possible to assess how effective this legislation would be and as such it was inappropriate to transplant the English Act’s measures to Scotland until such a review could be conducted.

While there were concerns, the majority of respondents contended that there was a need for a national strategy and in order to ensure its effectiveness, legislation was required.
Q3. Are the duties proposed appropriate to enabling a national ASD strategy for Scotland?

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

- prepare and publish a strategy to meet the needs of children and adults with autism;
- consult with appropriate organisations and people; and
- issue statutory guidance to local authorities and health boards on:
  - the provision of diagnostic services;
  - the identification of children and adults with autism locally;
  - the assessment of their needs;
  - the planning and provision of services;
  - the training of staff;
  - leadership at local level.

The consultation document asked whether these duties are appropriate. 136 respondents answered this question of whom 103 offered their support for the proposed duties.

Some of those supporting the duties did suggest ways in which they could be improved and also recognised that the success or failure of the strategy did in many ways rest with the quality of the individuals delivering the service. Amongst these responses, the most common, expressed by 4 respondents was that the service delivered should be flexible enough to respond to the individuals needs of people with autism.

Many of those not explicitly supporting the statutory duties did not reject the duties proposed, but suggested ways in which they might be improved. Six respondents stressed the need for consultation with people on the autistic spectrum before determining what the duties should be.

Five respondents again highlighted concerns about funding and the need to provide funding to establish an implementation group and parents’ groups to ensure that the strategy is delivered effectively.

Five respondents highlighted the need for the strategy to be properly monitored and evaluated with one arguing that Her Majesty’s Inspectorate of Education should have a clear role.

Two respondents raised concern about the absence of the involvement of the criminal justice system in the strategy, mindful of the fact that those with an
autism spectrum disorder are three to four times more likely to come into contact with the criminal justice system.

Individual responses highlighted the absence of information pertaining to social support, advocacy, self directed support, employment support and short breaks respite.

There were, however, some respondents who suggested that the duties were inappropriate and ineffective. Five respondents suggested that the duties were unclear and uncosted and believed more detail was required if they were to have effect. Two respondents suggested that as the Education (Additional Support for Learning) (Scotland) Act 2004 was in place these duties were inappropriate and superfluous. One respondent suggested that there was already a framework in place to ensure an effective service is provided to people on the autistic spectrum.

**Overall there was a sizeable majority of respondents who favoured the duties as expressed in the consultation document. However, there were a number of suggestions as to how they could be improved upon and the Member will reflect on these when finalising his proposal.**

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

There were 136 responses to this question of which 93 argued that the proposed duties were appropriate to guide local agencies to take a strategic approach to autism services in their area.

Some concerns were expressed, however, about the effectiveness of the duties and seven respondents argued that a national implementation group should be established to monitor how effectively the strategy is being implemented in local areas.

Six respondents suggested there was general lack of clarity to the duties which might undermine the strategy.

Five responses suggested that the effectiveness of the strategy could be undone by the inexperience and lack of understanding of autism spectrum disorders amongst professionals and in particular teachers. These responses argued that for the strategy to be effective more training is required.

Four respondents argued that for the strategy to be effective there was a need for local implementation strategies and local leadership.
Three respondents reflected that the strategy will only be effective if it is properly funded and two respondents contended that only if the right individuals are in place will the strategy be effective.

Two respondents argued that the delivery of these services should be time bound.

Two respondents also highlighted the importance of considering public transport and ensuring that people with autism can access the relevant services.

Two respondents expressed concern about the difficulties in achieving multi-agency work due to the differing boundaries of health and education authorities.

Finally, one respondent reiterated the point that the duties ignored the Education (Additional Support for Learning) (Scotland) Act 2004.

Overall there was a sizeable majority of respondents who favoured the duties as expressed in the consultation document arguing that they could provide an effective guide to local agencies. However, respondents also set out a number of challenges to the effective implementation of the duties and the Member will consider these when finalising his proposal.

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

92 respondents to the consultation took the opportunity afforded by this question to provide comments on the proposal and more generally about the predicament of people on autistic spectrum.

23 respondents took the opportunity afforded by the question to welcome the proposal, intimating that it was long overdue. Other respondents welcomed the proposal for specific reasons. Four respondents welcomed the proposal on the grounds that it would give people with autism in Scotland parity with those in the rest of the United Kingdom. Four further respondents welcomed the proposal on the grounds that it should ensure that parents no longer have to battle and struggle to get services for their autistic children. Four respondents stressed that this strategy and the comprehensive provision of services to children with autism would benefit society. Finally, four other respondents highlighted the improved understanding and awareness of autism spectrum disorders that would result from the implementation of the strategy.

Two respondents argued that the strategy could only be effective if it was developed in combination and following consultation with people of the autistic spectrum.
Other respondents highlighted what must be in place for the strategy to be effective. Seven respondents argued it was vital that improved training was given to those professionals delivering the service to people with autism. Eleven further respondents articulated the need for the strategy to be sufficiently resourced.

In terms of what the strategy must deliver for it to be effective, six respondents highlighted the need to ensure that adults as well as children are provided for and are not forsaken once they leave school. Six respondents also stressed that for the strategy to be effective the difficulties in getting access to diagnosis should be alleviated. Three respondents also contended that it should seek to increase respect for people with autism and furthermore, seek to ensure that people with autism can use their skills to contribute to society. One respondent argued that the Bill must ensure effective multi-agency working to make the strategy effective for people with Autism.

A number of respondents highlighted ways in which the proposal might be improved upon. Two respondents suggested that it would be improved by taking account of work already ongoing in the field. One respondent postulated that it would be beneficial to widen the strategy to incorporate those with cerebral palsy, dyspraxia and communication disorders. One other respondent argued that the Bill should not be limited to people with autism and instead service provision should be improved for all children with disabilities. One respondent contended that every child on the spectrum should have an advocate to represent their needs; one contended that the proposal should have a greater role for parents; and one contended that to receive support it should not be a requirement to have been diagnosed.

Finally one respondent questioned the belief that delivering this service to people with autism would be expensive. He suggested that Services for people with autism have a reputation as being “expensive”. However, he argued this is often as a result of inappropriate or lack of support services being available at the time when it is needed and the consequent impact of this.

Conclusion

The Member very much welcomes and appreciates the interest that has been demonstrated in his proposal.

The responses to consultation have affirmed many of the Member’s concerns about the inadequacy of services to people with autism. The responses have also highlighted new information, which will be drawn upon in finalising the proposal.