

## **SUBMISSION FROM EDINBURGH AND LOTHIAN ASPERGER SOCIETY**

1. On behalf of Edinburgh and Lothians Asperger Society (ELAS), we welcome the introduction of the Autism (Scotland) Bill and look forward to seeing it develop into a strategy for autistic people throughout Scotland. Below I outline points that members of our society have raised in response to the points on the draft Bill, with comments on the Policy and Financial Memoranda following thereafter.

### **Draft Bill**

2. Section 1(4),(5) and (6). It would help people on the autistic spectrum if the revisions were done on a regular basis, with regular consultations with key stakeholders eg local groups, societies and service providers and their service users. Where there is no such group giving the opportunity for users to make consultations, we would support provision for people to reply directly to the Scottish Parliament.
3. Section 2(1). Also, under "provision of relevant services", you should specify, provision of unobstructed access to diagnosis. There are still too many stories in the autism scene about regional variations in difficulty of getting diagnosis, and of people with autism finding their GPs resisting it and trying to rubbish their symptoms.
4. This is why no group that only allows in people with autism who have been diagnosed, is a genuine voice for the autism scene at all. Any such group is not entitled to count as a "key stakeholder". The bill needs to specify this, otherwise anomalies like that will be allowed to happen, devaluing the results of all stakeholder exercises.
5. Also, we note a perception amongst GPs that autism is a male-only condition, making access to diagnosis more difficult for females who can be misdiagnosed or brushed off. Part of the problem is that autism manifests differently in women and GPs should be informed of this.
6. Health services should be aware of the potential for misdiagnosis for all who think they might be on the spectrum,
7. Section 3. Thank you for including some committal specific types of service to be included in the "statutory guidance to local authorities and health boards ". These specifics make it worth doing.
8. Section 2(2). Waiting a year after the bill, for it to happen, also seems very long. The timescale for creating the strategy itself is shorter.

9. You should add to the duties around compiling the strategy, a duty of responding to issues input by any person who is engaged with autism or attention deficit in any way.
10. Local authorities (or combinations of adjacent ones) to be required, and funded, to set up autism specific resource centres in their local areas, on the model of Number 6<sup>1</sup> in the Lothians, to ensure more uniform provision of such services throughout Scotland. Alternatively, such centres could be situated locally but run by central government, as a way of pre-empting a postcode lottery in such services.
11. We would support provision for school pupils with autism to be given their education in mainstream schools, but with more specialist places available for them and with an appropriate education for their needs within such schools.
12. Thank you for being specific about who "key stakeholders" are, who there will be a duty to consult. But how will you always know that the key stakeholders really do represent real autistic folks and what we really want to say? The only way to be sure is to provide that individuals, not just organised groups, are heard. It includes a provision for any person to submit to the strategy makers a challenge against the validity of any "key stakeholder" group. The grounds for challenge would be, that the group has treated any autistic person unjustly and has excluded them, or has spoken for them falsely, or has ignored an issue raised by them and relevant to the item being spoken about.
13. How more obvious than that local groups will want and need a voice on local needs? Or that the existence of a local group is a local need, and that means in many places not yet served? But for a local group to be a genuine voice its workings have to be democratic and uncorrupted, as ELAS described in our previous submission [consultation held by Hugh O'Donnell on the draft Bill]. Whether we are writing to the strategy makers, to a local autism services coordinator, or to consultations like this one, no group is a fair or genuine voice if it has a leader with a personal veto power over everything the group might wish to say, and over members raising issues in meetings, and even over what members are allowed to contact each other about.
14. This needs to be specified in the bill in its description of key stakeholders. Otherwise, the check on how fairly a group is treating its members is to provide for individuals to raise directly with the strategy makers any going wrong of the group's scrupulous fairness.

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<sup>1</sup> One-Stop Shop for adults (16+) with High Functioning Autism (HFA) or Asperger Syndrome (AS) who live in the Lothians. For further information, see— <http://www.number6.org.uk/>

15. Section 5(2). Why do we have to wait two months after royal assent for the Bill to come into force? That's just more delay. The Bill already allows some time slack to allow for the strategy and guidance to be written. The Bill should come into force instantly its passed.

### **Policy memorandum**

16. Paragraph 24. Encourage more awareness among employers about autism and the difficulties faced by people with autism in the work environment, also equally stressing the benefits for certain types of employment.
17. Paragraph 28. Says "Even with a diagnosis it is difficult to get support because services do not fully recognise and meet people's needs." For example we express concern, within some autism organisations for certain aspects of their services such as not willing to make any commitment to deal with issues raised personally by people with autism. Eg, in all its work on employment it has never said a word about the bodily sensitivities in autism that prove a basic biological right for there not to be dress codes.
18. Paragraph 26. Its helpful to have Scottish Autism Service Network's (SASN) information on the low employment rate for people with autism, specified as a pressing priority of economic inclusion that the strategies need to deal with.
19. A list of guidance points suggested by ELAS members regarding the Policy Memorandum, although not exhaustive, is as follows: vocational assessment for people with autism at age 15/16/17; pupils being kept up to speed on their strengths, weaknesses, and fundamental school subjects; career paths for people with autism on graduation and specific training, including placements to accustom them to work environments; systematic instruction in life skills; social guidance including making friends and dealing with awkward people; drawing upon experiences of senior people with autism.
20. Also please note that the diagnostic criteria for autism and asperger syndrome will change, bringing both conditions under the heading for autism, and this should be considered in policy making.<sup>2</sup>

### **Financial memorandum**

21. You have set out details of why there will be a cost saving exceeding the cost of doing the strategies. As in paragraph 38, limited resources to greatest effect. The antagonistic Scottish government response to the Bill seems to let itself down by just ignoring these costings, it gives an

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<sup>2</sup> See the following sites:

<http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=97#>

<http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#>

argument for keeping services piecemeal based only on stating vague likelihoods about cost of doing the strategy work, that are uncoded and nowhere refer to the bill notes content in any detail. Nor does it answer the financial memorandum's case that services that are more planned and geographically even in spread, instead of piecemeal, will pay for the strategy in cost savings.

22. The consultation allowed us to highlight many specific problem issues, which any strategy meriting to be called complete needs to cover. It is a step backwards that the bill is not specific in any way about the strategy's contents, and that the notes say this is intentional. Even "the provision of relevant services" could be described more securely as "the provision of all relevant services". In the Financial Memorandum, paragraph 29 states that "the bill does not dictate the content of the strategy at all." This leaves the strategy's content so uncommitted and unspecified that it does not guarantee it will cover what is seriously needed at all. This is a missed opportunity. Eg, our last submission [to Hugh O'Donnell's consultation] showed with details how access to buses without communication problems arising can be an issue everywhere. If this is known as a fact, then it could be specified as an issue whose progress needs to be looked at everywhere.
23. Paragraph 29 of same, says you want to address the postcode lottery, unevenness of services, then do it committally. You will only do this if you specify it as an item that has to be included in the strategy. Yes it means requiring this item always to be there in the strategy's content. If you have an objective to do something specific, then you need to put it specifically in the bill. Otherwise a gap is left for the objective not to be met.

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