

## **SUBMISSION FROM THE SCOTTISH SOCIETY FOR AUTISM**

1. The Scottish Society for Autism (SSA) is the largest provider of, and longest established, autism-specific service provider in Scotland, with an international reputation for the quality of our work.
2. 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. Imagine if someone with defective eyesight was told that on reaching their eighteenth birthday they were now an adult and could no longer have spectacles!
3. We do not understand fully the level of need for people with autism in Scotland throughout their whole life journey. There are significant gaps in our knowledge and understanding of the demographics of the autistic community in Scotland. One phrase used to illustrate this is the “iceberg of illness” – intended to convey that much of the problem lies beneath the surface and is not readily visible. It is known that autism very often occurs with other impairments, either in terms of learning disability or physical disabilities. Autism can occur on its own, but also with additional (co-morbid) conditions: learning disability, mental health problems (anxiety, depression, and psychosis), behavioural (tourettes syndrome, attention deficit hyperactive disorder), learning difficulty (dyslexia). Depending on the dominance of these characteristics, people may be cared for in the health sector or by social services and also in too many occasions in the criminal justice system. The total provision of services is unknown, as is the number of people who slip through the net altogether. Clearly even taking into account all the other related and co-morbid conditions, the numbers of people slipping through the net must be very large.
4. 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. The world of adults with ASD is further complicated by the fact that adults also are entitled to choice in their lives. It is essential to remember that people with autism may not share the views of “neuro-typical” people in relation to what makes a positive outcome in their lives. Outcomes for people with autism may be unique.
5. This division is also reflected in the structure of government, where different ministers have responsibility for the education from those providing services in health and social care.

6. We therefore fully agree that a national strategy for autism in Scotland is essential.
7. I attended the first meeting called by the National Autistic Society (NAS) to explore the possibility of such an autism bill and together with my senior management team and my board of directors, gave considerable thought to the proposition.
8. We strongly support the case for an Autism Bill for Scotland in the long term, but it must be one which delivers real benefits for people with autism, and their parents and carers.
9. Although the concept of this Bill has evolved considerably this year, the original proposition was broadly to import the Westminster Act to Scotland. Our views, which we have expressed to the NAS, and in earlier consultations are as follows—
  - The Westminster Act, transplanted to Scotland would not raise standards significantly for service users or potential service users – Scottish local government could quite legitimately claim to be doing all of that already
  - If such an Act were realised, we would still have to try to bring about legislation based on the strategy which would be developed after the first Act, and at that point politicians could easily say "we've already done autism"
  - If the Bill fails, politicians would say "we looked at autism and rejected the need for legislation".
10. In other words, we may only get one shot at this, and wasting the opportunity on a Bill which fails to deliver real rights for people with an ASD could set us back years - in fact far longer than if we wait and do it right first time.
11. The whole timetable is being driven by the next Scottish general election, and this is an arbitrary constraint which is inappropriate to the scale of the task and the amount of research required properly to formulate strategy. When I asked the NAS chief executive officer, Mark Lever, why he had done it this way round in England, his response was that it was entirely down to expediency – the opportunity for a private member's bill was there, and they decided to take it, even though he accepted that ideally strategy should precede legislation. Therefore even the NAS freely acknowledge that this is not the optimum way to proceed.
12. I am very keen to participate in the development of an autism strategy for Scotland, elements of which we might then attempt to turn into law. For me, strategy remains an essential first step, followed by legislation, not the other way round.
13. Regarding the research underpinning the Westminster act, the National Audit Office report much quoted by the NAS is very useful, and indeed some of the statistics are nothing short of startling. Unfortunately there is

considerable scepticism about their applicability north of the border, and some not insignificant work would be required to “kilt” the report.

14. My role as chief executive officer here has involved restructuring of the SSA and equipping it to reassume the leadership of autism strategy in Scotland. I have now completed that restructuring and have created a new division which *inter alia* will deal with knowledge management and the development of strategy. We will continue to work on the slower but surer strategy development process, with a view to making costed proposals for government intervention at a later date.
15. The NAS initiative also cuts across other ongoing workstreams including that of the UK Autism Alliance, which we consider to be of greater rigour and value in the long term.
16. Therefore, when the NAS asked me if the SSA would collaborate with the project, my answer had to be “no”. I personally regretted having to take this stance, we are after all on the same side, but in this case we considered that the initiative is, on balance, counter-productive.
17. There is a history of the NAS making interventions in the Celtic nations with devolved administrations, without reference to the National Societies within Scotland, Wales and Northern Ireland. The NAS recognises that these national societies have a different role from small regional societies within England, and that they have a strategic leadership role within their own countries, but their actions belie a commitment to this principle.
18. The UK Autism Act, delivered by a similar route and philosophy to the Autism (Scotland) Bill, has proved to be a major disappointment to a great many people. Originally seen by many in the autism community as at last offering the prospect of real protection and conveying real rights for individuals with an ASD and their parents/carers, the strategy eventually produced was so watered-down by affordability constraints that it represents very little advancement in terms of rights. As a result there are many disappointed and disillusioned people in the autism community south of the border.
19. Finally I would like to address the question asked in earlier consultations - are the duties proposed appropriate to enabling a national ASD strategy for Scotland?
20. I would say in part only, they are incomplete. Perhaps the greatest weakness is that it has not been costed – except for some exceptionally woolly projections based around the NAO report in England. I have listed earlier some of the intersections between autism and other physical and mental impairments. The costs of attempting to address the entire spectrum of disorders could be astronomical, and yet we must recognise that in these straitened times, budgets will be contracting, not expanding.

21. Proceeding on a wide front is therefore likely to produce advances which are so small as to be indistinguishable from no movement at all in terms of rights for the individual. This has indeed been the unfortunate experience of our friends and colleagues in England.
22. We consider that it would be better to proceed on the basis of limited, costed interventions – such as the excellent work which has been done in Glasgow on the over-representation of young men with asperger's syndrome in the criminal justice system. This is an obvious “win-win”, but there are other areas where for modest expenditure, real benefits could be derived for significant segments of the autistic population.
23. We would recommend that the strategy address the following process:

**Quantified Mapping of  
“Disability Space”**



**Quantified Mapping of  
Service Provision  
Across all Sectors**



**Unaddressed  
“Demand” or “Harms”**



**Problem - Specific  
Costed Interventions**

24. It is our conviction that this would derive much greater benefits for any given level of expenditure.
25. I have however participated in the current Scottish Administration's external reference group's project to develop an autism strategy for Scotland. While far from perfect, this at least has the advantage of addressing the gaps in our knowledge and remains open ended in that it will be an evolving strategy with annual reporting to ministers. It also contains more “output” recommendations.
26. It is my view that adopting this strategy now would allow us to understand the total cost of addressing the needs of everyone with an ASD in a joined-up fashion, and allow us eventually to devise an autism bill for Scotland which is affordable, sustainable and delivers real and significant rights and benefits for people living with autism in Scotland.

Alan Somerville  
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