

SUBMISSION FROM LINDA PATERSON

Is there a need for an autism strategy to become law?

1. Although I can understand the argument that there is already legal protection for young people on the autistic spectrum through the Education (Additional Support for Learning) (Scotland) Act 2004, and I would be reluctant to advocate additional legislation if I felt this was unnecessary, I do feel there is a need for an individual Autism Bill. I have arrived at this conclusion through both personal and professional experience.
2. My son has Aspergers Syndrome, but because he is high functioning, this was never picked up by professionals. I started the process of him being assessed, as I was becoming increasingly aware of his social difficulties as he moved through primary school. We got his diagnosis towards the end of primary, and liaised with the school regarding this. He managed to cope in primary school, even though the latter year and a half was not a happy time for him.
3. The real problems started when he moved up to academy level. Because he was considered too high-functioning to be in a MICAS base, he was left struggling to cope in the mainstream. Although my husband and I had had a transition meeting at the primary school with staff from the Academy to flag up our concerns prior to him starting, none of the information which we felt should be passed on to staff who would be teaching him was actually passed on. Our son had a miserable time for a year and a half, during which we watched while his mental health consistently deteriorated, despite regular contact with his guidance teacher to raise our concerns. Eventually, half way through his second year, fearing that he was sinking into clinical depression, we took the decision to take him out of school and home educate him.
4. Our decision was made easier by the fact that at the time I was running an advocacy service for parents of children with additional support needs in education in Grampian, set up as a result of the 2004 Act. Over 70% of the parents who made contact with the service had children on the autism spectrum, and were struggling to get support in order to make life half-way bearable for their children (and themselves). Problems were particularly apparent within secondary schools. The whole set-up of secondary schools can be a nightmare for young people with autism – indeed, it would be hard to come up with a system more likely to create difficulties for them, given the numbers of people they have to contend with, the constant changes of environment, the noise and disruption, and often also being the target of bullying, teasing and exclusion by their peers. It is hardly surprising that young people with autism are extremely likely to develop mental health problems.

5. On top of this I became aware that there was a huge lack of understanding amongst school staff about what autism is and how it affects people. Some of the parents I spoke to told me that their children were so emotionally distressed that they were even talking about suicide. The response of schools to this demonstrated that they were ill-equipped to deal with these kinds of issues. One response to one mother who raised her concerns about her son's suicidal thoughts which sticks in my mind was "he needs to stick in, because he has his exams coming up".
6. Because of my experience in the advocacy service I knew that in my own authority area of Aberdeen City nothing actually existed within the education provision available which would meet my son's needs. Taking him out of the system was the best decision that my husband and I ever made, as we now have a relatively confident and emotionally intact son. It would not have been our choice to home educate, if there had been suitable provision available. It was a choice borne out of necessity. During my time in advocacy I was lucky enough to attend a talk on Aspergers Syndrome by Tony Attwood, probably the most internationally recognised expert in the field. He described the school environment as being "toxic" for some young people with Aspergers, and this was certainly the case for our son.
7. Another argument in favour of there being a specific Autism Bill is that the 2004 Act only covers children and young people. It is well documented that many adults with autism spectrum disorders struggle to find and retain employment, and are often very socially isolated. Not surprisingly, this takes a huge toll on their mental health. Many of this group are talented and capable people, with particular knowledge in certain areas, but they are cast aside by society because of their difficulty with social skills, and their apparent oddities. This is a huge waste of talent and abilities, not to mention the fact that it is intolerably cruel to individuals with autism.

Guidance provided under the Bill

8. I think the guidance section of the Bill is crucial, as this can give a real focus to what needs to be done. Assessment is vital, and, in my experience, currently provision of assessments is very patchy, with some people having to join long waiting lists. When the Education (Additional Support for Learning) (Scotland) Bill came out, there was a great theory that everyone who required additional support was entitled to it and only needed to ask, regardless of whether or not they had a diagnosis. The idea was to avoid "labelling" children. The reality on the ground was that it was hard enough to get additional support even with a diagnosis, so without one there was no chance. This was the situation in my area four years ago when the advocacy service I was running closed down because no funding was

available, despite it having been a extremely successful pilot, and I have no reason to think the situation has changed drastically since then.

9. I took the decision to pursue a diagnosis for my son as an insurance policy – although not wanting to label him, I knew that if we didn't have an official medical opinion to back up what we were saying we ran the risk of being viewed simply as “neurotic parents”.
10. There is a real opportunity to look creatively at what services and education, in what form and in what kinds of environment, is best suited to those on the autistic spectrum, looking at current examples of good practice that are already taking place.

Local authorities and NHS have a duty to have regard to guidance

11. This is crucial, as there is little point in issuing guidance if there is no requirement for those in authority to pay any heed to it.

Additional comments

12. I think the introduction of an Autism Bill would be a great step forward in raising awareness and understanding about autism spectrum disorders, and in trying to improve the services and opportunities which are currently available to those affected by autism.

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