

## **SUBMISSION FROM JACKIE ORR**

1. I am writing to give evidence in regards to the Autism (Scotland) Bill. My child has a diagnosis of autism and has multiple and complex needs and I would like to put forward some points for consideration.
2. I would like to hope that a specific law for autism would be beneficial and have a practical use for individuals with autistic spectrum disorder (ASD) and their families. To incorporate guidelines and requirements that professionals must follow.
3. In my own experience it has been very difficult to get information, help and support from agencies which are supposed to do this, namely education departments, NHS etc. In fact my own local authority has been particularly difficult to deal with.
4. With the threat of financial cutbacks (which have already started and are having an impact), I have a sense of unease that the already limited help and support which is available will be even harder to obtain or will no longer exist.
5. From experience I have to say that my child has been refused a co-ordinated support plan, even though my child had occupational therapy, physiotherapy, speech & language therapy and social worker. As a result of that refusal, occupational therapy discharged my child. With physiotherapy following shortly afterwards.
6. We have encountered many difficulties with education and have lots of written evidence to prove all the trauma we went through and if anyone is interested to know more I would be happy to give further information on what exactly happened in primary school with my child. The extreme measures a head teacher went to were quite extraordinary and I had to remove my child from that school. During this time we were left unsupported and at one point I felt bullied and intimidated by the education manager to accept a mainstream school which was unsuitable for my child. I put forward a complaint to the chief executive of the local authority and this was upheld. However the education manager continued to be adamant about a particular mainstream school.
7. I had put forward a placement request which was refused by the same education manager. I enquired about a primary school specific to autism and was told by the education manager and the head teacher of that school, that there was a child within the school who "was too violent" and "would be a danger to my child". I have to assume that this child was not a danger to the other children within that school. I had no option but to home school my son but this was not ideal and we continued to be left unsupported throughout this time.
8. The NHS services have proved difficult and we have been refused an assessment by occupational therapy, the reason given was that "they do

not have trained staff to deal with autism" This was only a few weeks ago.

9. A senior physiotherapist stated to me that "we do not have children with autism on our books".
10. I feel that this is a shocking state of affairs and I have to point out that my child has physical difficulties which is why I requested these assessments via a senior medical officer.
11. I have put forward some of the experiences we have had in order to clarify why I feel it is important to make sure that there is training made available to all NHS services and educational services.
12. I feel as a parent that there is still a fundamental lack of understanding of this condition. The impact of this lack of understanding and support not only affects on the child with autism but also the family.
13. I would like to add that there are no leisure facilities available for my child. When I try to access a class at my local sports centre, the local authority inform me that they do not have trained staff or qualified disabled sports coaches so my child cannot participate. However, under the school umbrella of inclusion, any sports activities provided by the local authority and leisure services, my child is expected to join even though they do not provide trained staff for disabled. My argument is that they cannot have it both ways.
14. My child attended swim classes on a one to one basis and I asked about the coaches qualifications and if there was an achievement programme for my child. I was informed that the coach was only a swim instructor but was not qualified for disabled. I was informed that they did not provide any achievement programmes for disabled. I have to wonder what my local authority considers a disability but in my own personal experience autism does not appear to be a consideration.

Jackie Orr  
8 October 2010