

SUBMISSION FROM JACKIE McDONALD

My experience of the present Education (Additional Support for Learning) (Scotland) Act 2004

1. This serves as written evidence for the Education, Lifelong Learning and Culture Committee's consultation on the Autism (Scotland) Bill. I am aware that at present there is an Education (Additional Support for Learning) (Scotland) Act 2004 in place, which unfortunately, is not working for my son.
2. My son was diagnosed with Asperger's Syndrome in December 2008 despite our noting of symptoms in 2006. Our experience as a family of the 2004 Act was appalling. When my son started school, I already knew that there would be issues, so I made sure that his teachers knew that I was committed to his learning and in letting him achieve his true potential. This however, was not a welcome idea, even though we are continually advised as parents to take an active role in our children's learning. I would firmly support an autism Bill for Scotland. From when parents have noted autistic tendencies in the child, this should be addressed and professionals assigned for the child so that these are either diagnosed or eliminated.

How autism is affecting us

3. It was a long and painful journey for my child before he had the diagnosis. Autism does not only affect the child, it affects his siblings, his entire family and the whole society in which he lives. My son finds it difficult to make sense of social rules, he cannot read facial expressions, and he finds it difficult imagining things as he is very literal. I think as he gets older and his needs complicate, legislation for autism is needed to aid him and many other Scottish youngsters with autism. I strongly think that if there is legislation in place this will guide all practitioners involved in the care of persons with autism.

Intervention

4. In my specific case, if intervention was done earlier, my son's life would have taken a completely different angle. Sadly a lot of families in Scotland are still struggling while their children's needs are not met. I strongly think that all individuals who have autism should have an individualised care plan which is reviewed at least every six months. I also feel that the government agencies would save a lot of time and money, if every professional knew their role in the care of young people with autism.

Education/training and gathering expertise

5. I believe universities and colleges should include autism spectrum disorders (ASD) in their training of students, especially students who will work with individuals with autism. If teacher trainees and nurses for example, study a module of ASD, this would mean that most people are made aware of the difficulties that persons with autism have, the legislation would have appropriate guidance and code of practice for all professionals in dealing with individuals

and their families. Parents need to be recognised in gathering information about their children.

Open communication

6. In my experience I was always on the phone trying to “chase up” professionals on what they should do. I would urge that agencies ought to be open lines about sharing of information for caring for individuals with autism. Once a child is identified as having additional support needs, a care plan is drawn and a multi agency meeting is set up and review is done routinely.

The fear of forgotten children

7. I feel that once the legislation is in place most children would access the curriculum effectively. Once the identification of needs is done, the next step would be how those needs are going to be met in trying to help children achieve their full potential. At present Scotland is implementing Curriculum for Excellence; autism legislation would validate this bold gesture where children are learning, at their own pace, and learning is child centred.

Leisure access

8. I would hope that the Bill for autism would stipulate and include guidelines on how children with autism can access leisure activities. A lot of children on the autistic spectrum are not socialised, as their parents are afraid to question the rules of leisure activities. Many parents or carers of children with autism do not send their children to extracurricular activities because, too often, these children are rejected during these activities because they are too excited or their behaviour is peculiar. In my experience I took my son for Taekwondo at 5. He was very well behaved for the first 30 minutes, but in the last 10 minutes he ran around and pulled other children's belts. The instructor told me that “I cannot be doing with that! This child needs to do as he is told and he is not to come back”. I was hurt by his comments because I explained to him, at the start, that my son has behavioural problems.
9. My son was only 5 years of age and clearly this man had judged him and decided that he did not want him to return. Despite him thanking me at the start for sharing the information and saying he will do his best. I would hope that a bill for autism in Scotland would suggest that all children are included as much as possible in all extracurricular activities so that they can feel a part of their society.

Provision of childcare for children with autism

10. As a parent of a child with autism, I know how hard it is to get childcare for him. On many occasions I have been told by childminders that they were not happy to watch my child as he has autism. I have had to give up on two jobs because of childcare issues. On one occasion a registered childminder told me that she “cannot be doing with a child that does not do what he is told” (a common theme apparently!). These comments are damaging to the self esteem of both

the youngsters and their parents. I believe childminders need to be open minded about the fact that all children are different and in particular the fact that the brains of children with autism are 'wired differently'. I would hope that legislation for autism would stress that all parents have a right to have their children looked after in a safe environment without the fear of discrimination.

Mental well being of the youngsters and their parents

11. As a parent of a child with autism, my mental health has suffered tremendously to the point of mental breakdown. This was due to the lack of support and understanding by professionals who were supposed have seen this and dealt with it. The mental health of youngster suffers too and this is a shame. Presently the mental health of children with autism is suffering with many of them having clinical depression, as they just don't feel a part of our society.
12. They become conscious of the fact that they are different from their peers, they do not have friends, they end up being rebellious and sometimes they get into trouble with the police as they have not been socialised. I would hope the Autism (Scotland) Bill would take this into account and seek to protect the mental health of individuals with autism as vulnerable adults or children.

Examples of good practice

13. While my son and I have had bad experience in the first two years of his school life, it would not be right not to indicate instances where we have had good practice. When my son was finally given an appointment with a child psychiatrist, it was good talk to someone who really listened and understood the issues we had. At present my son gets some support at school but this is being reviewed and there are threats that it might not continue, this is due to financial constraints. The support that my son has been getting for the last two years is tremendous, the trouble is he regresses from time to time, he needs the support continuously and I would hope that it remains so he may fulfil his true potential; especially that Falkirk Council is trying to get it right for each child. The only shame about it is one has to fight to be heard and surely it need not be like that.
14. In conclusion I am supporting the Autism (Scotland) Bill as lives of youngsters could change tremendously if guidelines were clear, straight forward and took into account the varied experiences of those who are autistic and those who support them. In addition, it is clear that the 2004 Act is not working for the children with autism.

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