

SUBMISSION FROM JOHN COLLINS

Support for the Autism (Scotland) Bill

1. No more promises and recommendations - we now need action backed up by law. This won't change things overnight but then that's not realistic. A bill is probably the start of a ten year journey that will lead to real change and save public money in the long run. In contrast, the journey we've had to take over the last ten years has hardly taken us to the end of the street.
2. Parents are often aware early on that their child is experiencing difficulties which are different from that of their peers, but some professionals have limited experiences of autism spectrum disorders (ASD). Early diagnosis can mean the gateway to services and support. Services such as local social work teams require children to have a diagnosis in order to gain access to services.
3. Waiting times for assessment are long. Depending on where you live, parents can wait years for a diagnosis after concerns have been raised about a child's development. Not all diagnostic teams are as skilled at recognising ASD.
4. Speech and language is a valuable tool. However access to it can vary. Children in specialist provision have access to more regular speech and language as part of the curriculum but for children in mainstream settings, lack of resources mean it can only be offered in short blocks for a few weeks a year. Although early intervention is crucial, speech and language is also vital for young adults in secondary school as part of helping them to continue to make sense of an often confusing social world.
5. The 2009 report from the chair of the Additional Support Needs Tribunal Scotland highlighted that, although children with autism represent 6% of the additional support needs experienced by pupils in Scotland, over 40% of the references presented to them were with regard to autism. The tribunal is the last resort for families and education authorities and such a high percentage gives an insight into the particular difficulties experienced by pupils with autism in Scotland.
6. Transition to adult services is also a very difficult and tense time for young people and their families. All young people need support as they move to adult life but they mostly do this without support from professionals.
7. After school many young adults are expected to attend day centres which are geared up to supporting the needs of adults with learning difficulties.
8. Parents watch their children having to fit into what service happens to be available. A person may not have learning difficulties or mental health issues but these are the only settings where their needs can be met.

9. Young people with autism have the right to the same opportunities as their peers. To work, take up further education and to be an active part of the community. Many adults with autism become socially isolated and end up depending on their parents support in transition and the provision of appropriate services at the right time might help prevent this.
10. Some people do fall through the net and do not receive a diagnosis as a child. People with high functioning autism and asperger syndrome may have coped within school but have always struggled to fit in socially.
11. Without the structured setting of school and family life, their true difficulties emerge. Many people may present in the criminal justice system or in mental health services.
12. There are few services for adults that are autism friendly. The few adults with autism who have access to such groups see these as a lifeline. For some it might be the only contact they have outside their home.
13. There is a need for more services to be autism friendly so adults can make the most of their abilities and feel that they are a valued member of society.
14. At present services are patchy across the country and within local areas. Different services exist in different local authorities just a few miles apart and each will vary in their understanding of autism. Everyone who needs support should have equal access to services which meet their needs.
15. At the moment there is little joined up work between agencies. The health service is good at dealing with physical disability and mental health, much of social services deals with what are deemed as vulnerable children and adults.
16. Many people with autism and their families struggle to plug the gap and do what they can. A social worker on a brief visit may see a tidy home but have no understanding of the struggle it was to put on a brave face.
17. More understanding and a joint approach to the needs of people with autism and their carers would mean less family breakdowns and crisis situations which are emotionally costly to families and financially expensive for local authorities.
18. It is estimated by the National Autism Society that the cost of caring for an adult with autism in a care setting is around £1m in that person's lifetime. Carers are an unpaid work force providing a high level of care allowing an individual to stay in their own home.
19. However the caring role can be very stressful as a person with autism can become socially isolated so can their carers and families. Sensory issues

can mean ordinary family experiences can be difficult if not impossible. Carers are more likely to suffer from mental health problems due to the stress of their role.

20. Autism in the family can have an impact on siblings with them having to adjust to their brother's or sister's needs. Carers need support networks and access to courses that will support their caring role. Local carers centre and support groups are described by carers as being a lifeline and an opportunity to be with others who understand what they are going through. However, these voluntary organisations can only do so much and what is needed is for the Government to take a lead in sorting things out.
21. The Autism (Scotland) Bill must continue through the parliamentary process and an autism strategy, backed by law, is absolutely necessary for Scotland. It will make such a difference to the lives of so many Scots affected by ASD. This is a great opportunity to make a positive difference in the lives of so many people.

John Collins

Father of Anthony Collins 11 year old boy with autism

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