

## **SUBMISSION FROM STIRLING AUTISM PARENT SUPPORT GROUP**

1. We support the Autism (Scotland) Bill. We are a group of parents of children with autism spectrum disorders (ASD) that meet regularly in Stirling to share information, experiences and advice and to generally help and support each other. We also arrange social outings and social opportunities for our children. We are part of the national network of parents groups that are linked to the National Autistic Society (NAS).
2. We feel that change is needed at this time and new ways of addressing the problems that thousands of parents face on a daily basis must be found. Diagnosis for children is still a lengthy and difficult process. GPs do not seem to have any knowledge of autism, despite previous attempts to give them awareness through the web-based training set up by NHS Education for Scotland (NES) and the book of diagnosticians that was put together. Diagnosis of young people and adults is almost impossible, again we think because of a lack of knowledge or willingness to recognise their difficulties. Often, just because someone appears to be clever or superficially capable, it is automatically presumed that there is no problem and no need to provide help and support. Diagnosis is just a post code lottery and we need national leadership to sort this out.
3. We keep hearing professionals saying that early intervention is vital but the very services that can make a tremendous difference in the early years, such as speech/language therapy and occupational therapy, are practically impossible to access and when anyone is lucky enough to get these they are usually delivered in such a scant fashion that they seem to have little effect on the longer term lives of our children. It's all to do with money and a lack of trained therapists, we feel, but surely money well spent in the early years will have lasting effects that will stop families having crises later in life?
4. Much is made about the supposed improvements in education. Probably this is true for the majority of kids who don't have ASD. We see that some councils have responded by saying we don't need an autism law because we already have additional support laws for schools. This is missing the point. Our children continue to be excluded from class and activities, formally and informally, because the complexity of their difficulties is not understood by teachers and support staff. We are totally fed up with being told that our children are badly behaved, or not paying attention, or being troublemakers etc etc. If we are going to have a situation where kids with autism are in mainstream and are to thrive, we need national government to sit up and pay attention and make sure that teachers in training are fully trained in autism. We don't know the current situation but it is plain that they are not equipped and they don't have enough understanding about it to effectively get the best out of our children. This is a disgrace. Is it not a child's right to be given a suitable education, regardless of what difficulties they may be facing? If you are going to try to get it right for every child then do so – it shouldn't be Getting it Right for every Child (but not those with autism because it's too

complex, too expensive, too difficult to tackle, too common, too disruptive etc etc).

5. Criminal Justice – police, courts. Again we have little confidence that our young people will be fairly treated. When they become teenagers it's a really scary time and we need some form of national guidance for the police and courts so that we can rest assured that our kids are not going to end up with a criminal record, or worse, because of a simple misunderstanding that grows into something more serious. We think that if you went into any prison in the country you will find too many people in there who have ASD. Again, something like this needs national leadership to make sure we get it right. Councils can do nothing about this.
6. Employment. Why are 85% of people with ASD unemployed? Our children are generally no less capable than any other. OK, they would struggle with the social side of work but they could make a valuable contribution to society and the economy in future years if they were able to access proper support in the early stages of transition, college and jobseeking. This is a no-brainer in our view but you will no doubt still get people going on about how much it will cost. How much is it going to cost to keep thousands of adults on benefits and not contributing or paying taxes during the next twenty years and more? The autism law in England will hopefully tackle this eventually and a similar law in Scotland might allow joined up working via the Department for Work and Pensions (DWP) or some other employment/benefits agencies.
7. So too with independent living. Too many people with ASD are forced to live with their parents because there are no means to offer them short term support to live independently. Again it's a false economy. It saves money while the parents continue to look after their adult offspring but as the parents get older and pass away, the state will be left to pick up the pieces and somehow deal with thousands of adults who have never learned to be independent.
8. Inappropriate services. If you don't have a learning disability or mental health problems then you're abandoned. We're talking here about the thousands of people who should be working, living independently, going to college/university, accessing leisure instead of being shut away in their bedrooms, looking to all the world as if they are "normal" yet struggling terribly for the want of a little short term support to get them off and running. It's the way things are structured. NHS, social work and education don't communicate enough, don't share resources and planning, don't understand the complexity or the scale of the problem and seem to lack the will to recognise this. We dare say this is not universal and that in some parts of the country this happens effectively but again, it's just like the postcode lottery we mentioned earlier and nothing is ever going to change with regard to the whole country unless those we elected take responsibility to ensure that some form of national standards are developed and enforced nationwide. And we're not talking about audits or research or good practice or guidelines or

recommendations here – I'm afraid we've had enough of that approach in the past and we'll never get anywhere if we go that route again. We know what needs to be done and how to do it. The country is already awash with good practice guidelines – why don't we simply begin by putting them into practice?

9. We think that a legally bound autism strategy that tackled transitions, college, employment and housing would actually save huge amounts of money in the long run and avoid families and individuals falling into despair and crisis. It's our view that the cost of doing something different would be less than the cost of doing nothing different in the long run.
10. We could go on and on and on about this but we'll stop here. We know that a Bill isn't a magic wand or a quick fix. We know it will take years to sort this out. Most of our children are young enough to benefit in years to come from a proper, legally backed autism strategy. What we fear the most is that we will be hoodwinked again by being offered promises that no-one will keep or recommendations that no-one will bother to enforce and that our children will become a forgotten generation with no job, no qualifications, no home, no social life and no hope.

Stirling Autism Parent Support Group  
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