

## **SUBMISSION FROM BARRIE COOPER**

1. I submit my evidence as a professional who has worked in the field of autism for the last six years and as a parent of a 23 year old son who has high functioning autism.
2. I believe it is vital that Scotland has an Autism Bill similar in provision to that already passed in England. Over the past few years there have been numerous reports and recommendations as to how the needs of children and adults with autism should be met. These have been largely ineffective as they have no statutory backing and services have remained uncoordinated and hugely variable in quality in different parts of Scotland. Services received by families affected by autism and adults with autism are largely based on a postcode lottery and, in my experience, a large amount of luck!
3. As a professional I work with parents of children and young people who have received a recent diagnosis of autism. These families are often in despair having received a diagnosis and then having no idea where they can go to for the day to day help they require for their child. Many schools still struggle to understand or meet the needs of children with autism. There are exceptions and the higher quality of support provided by these schools needs more recognition so that good practice can spread to other schools where the needs of children with autism are not recognised. Unfortunately I hear far too many stories of children with autism hating school, failing to progress in their learning, being bullied and socially isolated, being excluded both formally and informally and meeting teachers who treat their autism as just bad behaviour.
4. Parents also struggle to access help from health authorities – many GPs and health visitors seem to have little or no understanding of autism and do not recognise the huge difficulties faced by parents. Children are often referred to Child and Adolescent Mental Health Services (CAMHS) teams – some of which are able to provide the right support and advice but many still do not see autism as an area in which they have particular expertise or even the need to assist families in either the short or long term. There is often little recognition of the mental health needs of high functioning young people with autism – many of whom become depressed as they become aware of their difficulties during their late teens and early adulthood.
5. Social work support for families affected seems to have reduced significantly recently. Many families are receiving little or no support and even struggling to obtain a statutory assessment of the child and the families' needs. This is leaving parents struggling with day to day issues such as aggression towards themselves and siblings with no chance of respite or more general support for the family. I have met many families who are hovering on the brink of breakdown and likely to be in complete crisis before long. Early support could prevent the family requiring significant intervention at a later stage and at huge cost to the local authority.
6. The speed, quality and availability of diagnostic services vary greatly across Scotland. Many parents have to wait far too long to have their children

assessed – adding to their levels of stress as it is rare for parents to receive any services at all prior to receiving a written diagnosis. I also meet many parents who feel that they may be on the autism spectrum themselves. They struggle to find a professional who is able to carry out a diagnosis or to receive suitable support.

7. On a personal level, my wife and I have had to put a huge amount of time and effort in to seeing that our son has received the support and services he has needed at different times of his life. We have had the advantage through our professional experience of having more understanding of the services that should be available for him. Nevertheless accessing the right services has never been easy and continues to be a huge challenge.
8. Fortunately we were able to work closely with both his primary and secondary school staff who generally understood and recognised his needs. As he is intellectually high functioning, he performed very well academically at school but has always struggled with many aspects of basic day to day living. He was able to go to university where support was put in place for him but he found the social and academic pressures often overwhelming. That coupled with the difficulties of independent living resulted in major mental health issues. His and our experience of acute mental health services has been very variable – by good fortune he was treated by a psychiatrist who had an understanding of autism. However mental health nurses did not really understand his needs and told us that they receive no training in autism as part of their qualifications. He has since been able to complete a general degree at university.
9. He is now seeking work and, not surprisingly, keen to live independently of his family. He will require regular support when he is living away from home and an understanding employer if he is to find and stay in work. Without these we fear for his future health and wellbeing – particularly as we become older and less or unable to be his main support. There is very great potential cost to the state if he does not receive well co-ordinated support when he moves away from home.
10. It is essential that the Autism (Scotland) Bill becomes law in Scotland. There is no evidence that a strategy without statutory backing will make any significant difference. All people with autism require proper planned and relevant services that really meet their needs.

Barrie Cooper  
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