

## **SUBMISSION FROM FRANCINE ROBERTSON**

1. As the mother of a 23-year-old son with high functioning autism, I vehemently endorse the need for a coordinated national approach to meeting the needs of individuals with autistic spectrum disorders (ASD) in Scotland. I believe that the introduction of such a strategy is long over-due and is essential in order to meet the demands of the future.
2. To say that I have spent the majority of the last 20 years fighting for appropriate support for my son is, unfortunately, not an exaggeration: the struggle has been never-ending. However, the complete lack of knowledge and understanding regarding autism, displayed by a host of support agencies over this time, has been the most frightening aspect of all. In fact, the paediatrician we were referred to when my son was two laughed out loud when I suggested that autism was involved and then he went on to propose that, as we had two other children, we should “forget about him”.
3. 20 years ago acquiring an initial diagnosis proved to be almost impossible – my husband and I, therefore, decided to seek help out-with Scotland and ended up at the Maudsley Hospital in London where we did, eventually, receive a diagnosis.
4. Throughout my son’s schooling invaluable support and advice at was provided by Dr. Glenys Jones, Autism Research Centre, Nottingham University, and Jim Taylor and staff from Struan House School in Alloa. However, this support was only made available because I decided to search for it – staff at both nursery and primary school did not have anywhere to turn for advice.
5. Thankfully, the situation seems much more positive nowadays - early intervention strategies are in place in some areas and relevant support is provided by many education authorities within schools. However, very often the quality and amount of support offered depends solely on where a family lives – surely this can’t be fair?
6. Initially, secondary schooling proved to be a nightmare – again, a lack of expertise and understanding led to a harrowing encounter with the education department that culminated in my son moving to another secondary school. Eventually, with six standard grades under his belt my son moved onto college and is now studying computing on a part-time basis. (But this, again, has been fraught with problems, to say the least.)
7. At 16 years of age, my son was referred to a psychologist by the school doctor who was concerned about the possibility of depression. Once again, we were met with a wall of ignorance regarding autism and ridiculed for suspecting that my son needed support. So we battled on alone.

8. By the time my son was around 20, it became evident to us that he needed some sort of support. He appeared to be depressed, he was very aggressive and the strain was having a huge impact on the whole family. It should be pointed out that we did not have a social worker, or any other form of support or input. Looking back, it seemed to be that since we appeared to be coping we were left to get on with it – until a crisis erupted.
9. I can honestly say that I was totally unprepared for the events of the last few years. My father died from Alzheimer's disease and his death had a profound effect on my son's mental well-being. I asked for him to be referred to a psychiatrist who subsequently prescribed Prozac. When the suggestion was made that he, perhaps, would benefit from some sort of autism-specific "talking therapy" again this was dismissed as unnecessary.
10. Eventually, my son did see a psychologist who admitted that she didn't have the specific skills to help him and he was becoming more and more distressed. This whole situation culminated in my son being admitted to the local psychiatric hospital whilst my husband and myself were on holiday – the consultant psychiatrist came to our house and diagnosed him as being "psychotic". His sister and brother accompanied him to hospital where they demanded that he was released – this was agreed as long as the newly prescribed medication was taken. My husband and I returned home that night to find our son so drugged up that he could hardly stand. And so began another battle.....
11. This involved us finding someone, somewhere who could diagnose my son's problem. After much research we discovered Professor Tommy McKay in Dumbartonshire who provided a diagnosis of high functioning autism and highlighted a requirement for autism-specific cognitive behaviour therapy. We funded this assessment ourselves.
12. Unfortunately, at this time, another incident occurred which devastated our lives. My son was reported to the police for committing an indecent act and was, subsequently, charged, finger-printed and photographed. The behaviour of the sergeant involved was absolutely revolting - so much so, that the junior police officers involved were in tears and apologised to me afterwards. The "named person" who was there was also enraged and was sickened by the callous behaviour witnessed. Again, ignorance and a total lack of interest made a difficult situation unbearable and my son spent three months of his life convinced that he was going to be sent to prison.
13. Social workers were unable to give any support or advice so, once more, after much research I sourced a lawyer who had knowledge of autism and who was really supportive. Eventually, after collating character references/assessments etc. the case was thrown out by the Procurator Fiscal - but I received a letter detailing in no uncertain terms what the consequences will be if my son acts in this way again.

14. The diagnosis and recommendations from Prof. McKay finally led to my son receiving the specific support that he should have received many years ago. At 23 years of age he is attending autism-specific therapy sessions twice a month with Dr Anne Greig in Dumbartonshire – and the difference in him has been amazing. I must point out that Dr Greig provides a similar type of support for school-aged children within Dumbartonshire. I try not to think too much of the difference such input might have made to our family's life if our son had received this support sooner.
15. At the present time my son is progressing well at college and we employ a personal assistant who attends college with him. He also benefits from a local transition project which has helped enormously with his socialisation (he attended his first prom two weeks ago). He is learning to drive, is considering living more independently and would like to have a girlfriend. I look at him and thank God that things are the way they are. But who knows what the future holds? I shudder to imagine how things might have turned out in different circumstances – and sometimes wonder how many sons and daughters with an ASD are held in psychiatric wards or prisons in Scotland?
16. As his mother, I have spent the last 20 years battling to ensure that my son receives what he deserves and this has, unfortunately, taken its toll. I have today received confirmation of my early retirement (at 51) through ill-health from a job that I loved. I firmly believe that the never-ending stress and the continual fighting for support associated with caring for a child on the spectrum has played a huge part.
17. Living with autism impacts on each and every member of the family – feelings of isolation, desperation and guilt add to the day-to-day trials of family life. The quality of life experienced by such families should not depend on where a family lives or whether the mother or father has the where-with-all to fight for what their son or daughter needs. A caring society in the 21st century should ensure that legislation is in place to protect these most vulnerable and misunderstood individuals. It is time.

Francine Robertson  
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