

SUBMISSION FROM JANE MURRELL

1. My son, Michael, is 8 years old and probably has Asperger's Syndrome. I say probably because although we have had a 'private' diagnosis from a doctor in Glasgow Michael has still to receive his formal diagnosis through Child and Adolescent Mental Health Services (CAMHS) in Perth.
2. I struggled a little with Michael in his pre-school years but I felt that as I had no family support – either because they were no longer with us or lived a long way away – that perhaps I wasn't 'cut out' for motherhood. I couldn't really say what was bothering me – I sometimes still feel I can't really explain it – but there were differences. Sometimes we thought some of his differences were 'funny' or 'clever' but never really thought anything was 'wrong'. Certainly we attended all his development appointments with the health visitor and nothing was flagged up. There were some problems in pre-school which were frustrating and it was vaguely mentioned that Michael might need 'support' which was not explained and we felt we had been branded 'bad parents'. It was around the time we had our second son so put it down to excitement or his insecurity of having to share us with a new sibling.
3. He started in P1 and his teacher seemed to be telling us of a different (and seemingly to us) insignificant problem each day. He didn't want his photo taken on one occasion and on another he made a fuss because there was tomato on his lunch plate – we thought it didn't seem that serious. At one parents' evening, his teacher 'thoughtfully' informed us that he needed support – and when asked – said Attention deficit hyperactivity disorder (ADHD). We were devastated. We walked home in silence; when I saw Michael, I felt I didn't know him – who or what was he? I spent the next day speaking to the GP, health visitor almost hysterically and they were so kind – they tried to offer reassurances and between them referred us to paediatrics but warned of the 'long' waiting lists – we expected to be seen a year later. Somehow though we were seen within a month and just before Christmas we were told by the paediatrician that he did not have ADHD and to go home and enjoy Christmas.
4. Nothing much happened at school over the next few months and Michael seemed fine and more settled so as we were unhappy with the line the school had taken we decided to make some financial sacrifices and send him to an independent school. The problems came to the forefront from the first day. In short we struggled on for another year when the form teacher told us that he thought Michael might have Asperger's Syndrome – it was like P1 all over again. We thought – naively- that Michael had been 'tested' and there were no problems. We had continued to see the paediatrician one or two times per year and she kept saying that he was still young and not to worry. How could there be such a problem? I phoned the paediatrician and told her what had been said – she thought it might be helpful if she sent me through all her notes and letters. When they arrived I read them all from front to

back and in the last paragraph on the last page she informed our GP that 'Michael is increasingly presenting with the condition Asperger's Syndrome'. My world fell to pieces. We were told at this point that it could take years to be seen for diagnosis so we asked if there was a 'private' route we could take – we were concerned that without this Michael might be expelled. We paid for and got our diagnosis of Asperger's Syndrome. I made it quite clear at the time that Michael was to remain on the CAMHS list as this private diagnosis was to get information to inform his school. I received a letter a few months later saying that as Michael had had a diagnosis he was being removed from the list. I was furious – how dare they. I phoned and complained and insisted that his name was put back on the list in the place in the queue that he had been at. I discovered that this had been done as part of an exercise to try and reduce the waiting list which had been so poorly managed that it was only getting longer and longer.

5. Being at an Independent school we discovered that we were excluded from any support from the local authority. They would not entertain us in any fashion. I spoke to the educational psychology department and explained our problem and asked their advice. They too were very kind and met me and Michael, but we could only use that service to help us in the future should we return to local authority education. We struggled on – the local school (at that time) had a very bad reputation and I thought that Michael was better where he was. We managed to get some help for speech and language but because they 'cannot' go into schools outwith the local authority he could not benefit from any group or social exercises. The head teacher really seemed to want to help but it was out of his area of expertise. We had a glimmer of hope when we were told Michael's new form tutor had worked with autistic children before – we felt there was a breakthrough. We were so wrong. She was very negative, she had no idea how to deal with him and was quite frankly a disgrace to her profession. She used the traits of his disability against him and his school report was so negatively written we vowed to take Michael out of that school the sooner the better. The report was given in November – Michael was in his new school in February.
6. Michael joined his new school in a mainstream class but within one and a half weeks was moved to a separate class for autistic children. It has four 'full' time class pupils including Michael plus lots of other pupils who use the class on a part time basis. I was not happy that they had put Michael in this class – I felt it was a step backwards for him. However it soon became clear that he was now receiving the support he needed. Michael has thrived in his new class and I have no complaints. More than that, a huge cloud of stress and anxiety has been lifted from the whole family. Michael is more confident and has recently attended his regular class without a support assistant to do some maths and PE – something I imagined was many months if not years away.
7. Life is not perfect for us and never will be, but with extra support, children like Michael will lead full lives - some of them without support in

the future - but only if they have support now. I consider that since February this year we have been lucky to be getting the support that we have through Michael's schooling – but we are in a very small minority. I still feel that we could receive more as a family to help us and for the benefit of his younger brother who appears not to have any problems.

8. Our story is one of thousands and although we are currently happy (as we can expect to be) it can very easily change – lack of funding, lack of education for teachers, stretched support staff – all of these are too common and unacceptable. Once Michael moves to senior school who knows what will happen. As parents we need to be sure that the good that is being done now will continue for Michael and be available for all children that need it whether for a short time or for the rest of their lives. This should be given as a matter of course and we should not be left relying on charities for information and support.
9. You might be interested to know that Michael is finally undergoing his autism assessment – two years after being referred and four years after us first being aware of there being some problems. We are only at the beginning of this part of our journey but at least it has finally begun.
10. Thank you for reading my very abbreviated and short version of my story – I hope that it has given you an insight to the lives of one family dealing with the effects of having a child on the spectrum and the need for this Bill.

Jane Murrell
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