

## A Parent's Personal Experience

My name is Tesca Barnett-Osman, and my husband is just beginning his tour as the British Ambassador to Romania. We arrived in Bucharest at the end of May 2006, although our children remained at school and university in the UK. They will obviously be visiting us during the holidays, and are looking forward as much as we are to exploring our new home country. Sadly, our arrival was too late to attend this conference, although I knew in January that it was going to take place. I hoped to attend because I have a particular interest in autism - my son was formally diagnosed on his third birthday.

David's father and I were living in Germany at the time, connected to the British forces based there. I was a diplomat before I had children, and he was a television reporter. Both professional communicators. It was inconceivable to us that we, of all people, should have a child who could not communicate. But as we began to research more about the condition (until then, all we knew about it was how to spell it), we recognised all the "differences" described. Not only in David, but also in his paternal grandfather. And his grandfather's identical twin. It seemed obvious to us that this word was applicable to David, but knowing that his grandfather had got through life, married and weathered the problems that life inevitably throws at us all, we felt quite positive about his prospects. As parents, it was our responsibility to do the best we could to prepare him for adult life, just as we would for any other child. We found that the only thing you can do about autism is to educate. I had the chance to attend a conference very like this one, and received possibly the most important piece of advice ever. A wise paediatrician told me that the greatest need these special children had was for parents who would champion their interests tirelessly.

I took this advice to heart. I read everything I could find on the subject, although much of it was far too technical and medical for me to understand. But I did find ways of understanding how David thinks, and ways of helping him adapt to "our" world. I discovered that most of the neural pathways in our brains are laid down before the age of 8 or 9 years, so we focussed on teaching him as much as we could. With help from teachers and speech therapists, David learned basic skills: taking turns in games; asking for a biscuit and getting it; playing with other children; making eye contact; the rules of communicating with others, which we learnt intuitively. By his fourth birthday, the paediatrician who had given the original diagnosis was so amazed at David's progress that he doubted he would have been able to spot the signs again. He said that this was all due to the fact that we had simply accepted the fact, and applied ourselves to the problem. David went to school - a special class in a normal school - and learnt to read. Unlike most children, who might guess the words from the picture clues, he had to do it the hard way - by memorising the shape of every word. As a result, his spelling has always been excellent, and he has a phenomenal memory. Haircuts were a problem for a while, but eventually we got through that sort of practical problem too.

But it wasn't just David who was learning. I discovered a whole new world of ideas, psychology, philosophy, education, communication.... And possibly the greatest thing I learnt from David was a level of patience I never had before. I had to - getting cross with David only agitated him because he couldn't understand why. Then it would take hours to calm him down again. I learnt to lower my voice in pitch and volume if he appeared not to hear me, rather than raise it as one normally might. I learnt how to break difficult ideas down into simple blocks, so that I could explain things to him. This meant I had to think carefully before answering his questions. And I learned always to tell him the truth as fully as I could. When we lived in Poland, we were able to attend special education sessions at Synapsis, the Polish Autistic Foundation, which really made a difference, both to David's and my understanding. I feel that learning to help David has made me a better person.

We were open about the word "autism". When he asked, I told David that it was just a different way of thinking. This made me realise it was true. Most of us work on Microsoft systems, but for some applications, AppleMac is better. Ask anyone who works in design! There isn't a complete translation programme between these two systems, although there are some fairly good ones. And that's how I think of it - most of us are on Microsoft, but David is using AppleMac. Autists can be identified with computer systems in a much more direct way too. For a computer, there is only right or wrong, no grey areas for interpretation. Computers only "know" what has been specifically programmed in, they can't generalise. They can store huge amounts of data, but the more you store on your PC, the longer it takes to recover the particular piece of information you're looking for. They can't "read between the lines", or interpret the atmosphere between people. The joys of binary language!

Autism is becoming an increasingly common diagnosis all over the world. I don't think that means that its incidence is increasing, simply that we are getting better at recognising it. There have always been people who might have been seen as "idiosyncratic", "set in their ways", "happy in their own world". We all know people who have incredibly detailed knowledge of subjects that strike us as being boring, but they'll talk about it for ages without realising that your eyes had glazed over and you stopped listening. People who are great at the minutiae of a particular subject, but unable to see the bigger picture. People who don't like change of any kind. But they're still productive members of society, working as accountants, bus drivers, factory workers, car mechanics..... David is now 14, a healthy and happy vegetarian, and we foresee for him a near-independent life. He'll get a job, he'll pay his taxes, he might marry. All this has been simply through education, and completely without medication or other medical intervention. After all, he's not ill - he's just different

The diagnosis should not be the end of the world - just the opening of a new one. If the child's parents can accept the diagnosis, they can help that child adjust and learn about living in "our" world. And entering "their" world might show them a whole new set of horizons too. But parents are not going to be able to accept autism as simply "different" if it is stigmatised as an illness, a psychiatric disease, or something else negative. We all need to think differently if we want autistic children to develop into useful members of society. From my contacts so far with the competent authorities, I am sure that the future for Romanian autists will be much more positive. I sincerely hope that the good work begun at this conference will be followed through with the assistance of the various authorities, so that we can report on progress, developments and issues at a similar event next year.

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