

Down syndrome and Autism

This article was contributed by a parent-member of DS NSW, who has asked that the family's names not be revealed to protect the privacy of the young man.

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My son Charlie* has Down syndrome and Autism. He also has dyspraxia (a speech disorder that is very disabling for him) and a mild hearing loss (that does not seem to cause him any problems). He was diagnosed with Autism three years ago at the age of eighteen.

I have a Bachelor's Degree in Early Childhood Education, as well as a Master's Degree in Special Education, so you would think that I would have noticed that Charlie had Autism, but I didn't.

So what is Autism and what does it mean for Charlie? For Charlie, his Autism means that he has all of the following problems to a significant degree:

- Severe anxiety in unfamiliar situations, with unfamiliar people and in crowds
- Depression
- Avoids social contact
- Does not have self-confidence with others
- Hates people looking at him
- Hates speaking to strangers or being in a group of people
- Has some ritualistic behaviour and loves keeping things very neat and tidy
- Rarely uses eye contact, smiling or facial expressions when interacting with others
- Rarely greets others spontaneously
- Rarely looks for or offers comfort or affection at times of distress
- Lacks feeling for others or shows abnormal response to the emotions of others
- Does not share objects or food with others
- Does not respond in an appropriate way in social situations
- Has difficulty in developing friendships and social relationships
- Has difficulty reciprocating in a conversation with others (despite verbal ability)
- Becomes distressed over changes in routine or surroundings.

Characteristics I had previously assumed to be part of Charlie's Down syndrome turned out to be part of his Autism. The diagnosis didn't make any difference to him, but it made a big difference to me. It made a difference to how I handled him. I stopped stressing about certain things, accepted them and stopped fighting against them.

Having Autism affects Charlie's life in various ways. He really likes routines. For example, he wakes up at the same time every day. He gets dressed and his father walks him over the road to the bus stop. He has to have the same denominations of notes and coins in his wallet. One ten dollar note, one \$2 coin, one \$1 and one 50 cent piece. Nothing else will suffice. He will not allow us to drive him to work, or pick him up, even if we are driving past. He loves work so much that he hates to take a day off, even when he is not feeling well. He has been known to sneak out of the house when he is supposed to be staying home with a cold, an infection or a broken leg.

If Charlie cuts himself, or has a blood test he will not have a bandaid. When he broke his foot, he refused to have it plastered. It was fortunate he could walk on it and it healed on its own. He has had lots of blood tests and when he was small it took four people to hold him down (he is fine now).

He only has one bag, wears one pair of shoes and uses one wallet at a time. When he gets a new thing, he throws the old one away.

He gets so anxious before most social activities that sometimes we have to fight with him to go. We know that when he gets there he will have a great time. When Charlie goes to a respite activity, he has to get into the mini-

bus straight away and sit in the front, away from the others. Some drivers are nice, but some don't understand why it is so important to him.

Charlie does not make eye contact with people. He does not smile very often and he hates being hugged by anyone, except a ritual hug from mum and dad before bed. You can't talk to Charlie while he is eating. He is very focused. He always eats his food in the same order and he hates sharing his food.

Charlie's behaviours have never been used by him to manipulate others. Charlie cannot change his behaviour and a lack of adaptability, due to his Down syndrome, is taken to a whole new level by his Autism. By giving him structure, and accepting his limitations, we are not 'giving in' to what some might see as 'bad' behaviour. Sometimes we acquiesce and sometimes we persevere. We choose our battles wisely.

We find management strategies that work and then leave things alone. We do make him try new things (that we feel will be of benefit to him) a few times and if he cannot adjust, we re-evaluate. When he began work, we started him full time, as we knew from past experience that if we started him part time and tried to slowly increase the hours he wouldn't cope at all.

When Charlie was first diagnosed with Autism, I was initially shocked and upset. I thought "Here we go again. Yet another problem." However, in actual fact, the diagnosis was very helpful. It explained so much about the way Charlie operated in the world, gave me wonderful insights into his behaviours and helped me to deal with them. His specialist said there were certain things I could not change about his behaviour, and I was wasting my breath and energy stressing over them. For Charlie, some things have to be done a certain way, with no logic to it, and no reason why it should be so. The specialist said that the behaviour I could change was my own. The way I reacted to the weird and wonderful things he did.

When I found out Charlie had Autism, and I learned more about it, I could see which aspects of his personality were because he had Down syndrome and which ones were because he had Autism.

So how did Charlie come to be diagnosed with Autism? When he was sixteen, Charlie attended the NSW Developmental Disability Health Unit, a specialist clinic for people with intellectual disabilities, supported by the Centre for Developmental Disability Studies and Royal Rehabilitation Centre Sydney. Ultimately, he was referred to a psychologist and then to a Psychiatrist who treats many patients who have intellectual disabilities. The following is an excerpt from the Psychiatrist's report.

[Charlie] is an eighteen-year-old lad with Down syndrome...functioning in the moderate range of intellectual disability, probably in the upper part of this range. He can speak in quite complex grammatical sentences, marred by the considerable speech dyspraxia for which he has received endless input in the past with modest success. He rejects the use of any other communication methods such as pictures or signs. He has minimal literacy, vague numeracy, but reasonable basic self-care skills. ... I went over the Mini-PAS ADD, and it appears that the family filled this out quite incorrectly in a number of areas, particularly the page relating to Autism. In fact he is in the mild end of the Autism spectrum.

He has always been rather anxious and handles crowds poorly. He is not doing well at TAFE after a term, and the teacher wants to push him through hoping he will habituate, but I do not think he will. He is ritualistic in a restricted way, insisting on having his clothes in piles on top of surfaces in his small bedroom when there is plenty of space in cupboards and drawers, and he will put them over the floor. He has a large video collection which must be maintained in exactly the right state, and lined up. He used to line things up a lot as a child.

He is rather a loner, and is very happy spending time in his bedroom watching wrestling videos repetitively. He is still only capable of parallel play and tends to be on the outer with groups. [Mum] could not recall him using declarative pointing. He does not really seek to share his interests. He probably registers some awareness when others are unwell but is not solicitous.

He is very aware of having Down syndrome and clearly unhappy about this...[He] is well aware of the limitations his condition imposes, especially in comparison with the opportunities available to his three siblings. He feels that people are looking at him, and dislikes crowded trains. In many ways he is probably right that they are, but he is very uncomfortable with this.

As a child he was rather floppy, and this was felt to explain why he was not more closely responsive to cuddling, but in fact he stiffens to a degree that persists. He was not particularly ritualistic and he slept well unlike many people with more significant Autism.

He certainly is very fond of his sisters, and very close to them, so he is not totally socially impaired. Nevertheless I think that a mild degree of Autism is the right diagnosis, and is the cause of his underlying anxiety. I do not feel that he really has a social phobia type of anxiety even though superficially it does look similar. This has important implications for management as he will not be able to work through this anxiety and habituate.

I would be inclined to give up on TAFE. I would suggest that [mum] leaves him to his rituals in his bedroom to whatever extent is practical.

These days life is very good for Charlie. He has a full time job in supported employment. He travels to and from work independently, by bus and train. He participates in family life and travels interstate on his own to visit his sister. He has friends and a social life. He fits into the family well, and he is happy most of the time.

I wonder how many people have both Down syndrome and Autism. I believe that most people with Down syndrome exhibit some behaviours that fit onto the Autism spectrum, without having Autism. I also believe that there are some individuals with Down syndrome who do have undiagnosed Autism as well. Maybe this story will 'ring some bells' with other parents.

Disclaimer: I am not a doctor, and this article is not intended to give medical advice. If it resonates with anyone, see your GP or Pediatrician.

* His name has been changed to protect his privacy.

Further information about the dual diagnosis of Down syndrome and autism is available from:

- **Down Syndrome & Autism Internet Information Center:** www.disabilitysolutions.org/dsaic
This web page includes links to a special issue of Disability Solutions magazine, and to a email list dedicated to the discussion of Down Syndrome/Autism Spectrum disorder dual diagnosis.
- **Kennedy Krieger Institute:** www.kennedykrieger.org Type "Down syndrome and autism" into the search facility for a number of relevant articles.
- **Dual Diagnosis – Downs Syndrome and Autism** is a British family's web page about their son: <http://www.ds-asd.tk>

If you need additional information please do not hesitate to contact the DS NSW office on 9683 4333 or email info@dsansw.org.au

Charlie's Behaviours	Behaviours Associated With Down syndrome	Behaviours Associated With Autism (that I Previously Attributed to Down syndrome)
Preschool		
He hated any attention, being in front of the group	?	√
He always played by himself	?	√
He didn't cry much	?	√
He didn't flap his hands or rock or spin	√ (most children with Down syndrome don't)	√
He had limited development of play activities	√	√
He didn't speak. He only approximated vowel sounds until he was around eight to ten years old (which is very late for Down syndrome)	√	√
He had difficulties with toilet training	√	√
He didn't point to communicate with others (I didn't know that not pointing was an important factor in the diagnosis of Autism)	√	√
He was extremely distressed by loud or sharp noises such as fire alarms, concerts, etc	√	√
He was very difficult in shopping centers and busy places	√	√
He watched the same video over and over and over	√	√
Primary School		
He found it very difficult socially	√	√
He had significant speech and communication problems	√	√
He refused to get up in front of the class for news	?	√
He had a very short attention span	√	√
Adolescence to Adulthood		
He had increased levels of anxiety and developed depressive symptoms leading us to seek professional help	?	√
He had significant expressive communication problems	√	√
He had some (but only occasional) aggressive behaviour	?	√
He had strong resistance to change	?	√