

Polly's Piece

DEFINING THE DIFFERENCE



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I think we have a problem; maybe people with Asperger's and autism should not be under the same umbrella. It seems to me that we are dealing with two completely different conditions.

We know all about the similarities, but it's the differences that concern me at the moment, and it's the differences that are so apparent in the calls that I receive every week.

I get calls from people with Asperger's who say they need help with things like getting into mainstream school, getting into college, getting a job and keeping it, finding somewhere to live within commuting distance of their own community, making friends, getting a girlfriend, getting a diagnosis. Many are proud of what makes them special and proud to be a part of the Asperger's community, but they want the wider community to accept them for who they are and to help them find their place.

Parents and caregivers dealing with autism tell me what they need: a school or place that meets their child's needs without having to take the school district to court every step of the way; a curriculum that recognizes the overriding importance of independence and social skills; more access to specialized speech and language therapy; more access to educational and therapeutic approaches that can help reduce anxiety, improve behavior and enhance life skills; and medical and nutritional needs to be taken seriously as a matter of urgency. Perhaps most importantly, they need the support of doctors who can recognize and treat the various medical issues that plague so many of our children. They need someone to help them get fit and ready for learning, and, of course, they need an answer to the burning question that many are afraid to ask: what will happen to our children when they become adults?

Diagnosis doesn't feature in the autism wish list because I get very few calls from parents of children with autism asking for help with this; these requests come from the Asperger's community. A diagnosis of autism generally comes earlier and seems easier than does a diagnosis of Asperger's. It was already blindingly obvious when Billy went for his diagnosis at age 2. He couldn't speak, respond to his name, or pick up a toy on demand. In fact, all

he did was spin the psychologist's chair and bang his head against the wall and floor. It wasn't hard to figure out that he had autism, and it was a fairly quick process. Asperger's, on the other hand, is far less likely to be picked up at age 2 and often isn't diagnosed until years later. It seems, sadly, that too many people with Asperger's suffer for too many years without the support they need because the subtler manifestations of the condition are hard to recognize in their early stages.

Asperger's is no less devastating for the lives of individuals, but it's different for them. Their wish list has little relevance to children like Billy. Billy will never need a university place and is unlikely to be able to achieve a fully independent working and social life. In fact, he's unlikely ever to need many, if any, of the items on the Asperger's wish list. Billy has full-syndrome autism not Asperger's. His skills and needs are very different from people with Asperger's. Unfortunately, at the moment, people with Asperger's are seen as the "voice of autism."

Recently I attended a meeting on the future of people with autism. The organizers were terribly excited that the document that they were developing was based largely on contributions from "people with autism." "Aren't we lucky," announced this lady, "that people with autism have written to us and expressed their anger at not being able to do so much. It's fabulous that we have autism being represented by autism."

My heart always sinks when I hear this. Look, I couldn't be happier that people with Asperger's are getting their voices heard; they need and deserve that, but the voice of autism they are not; the voice of Asperger's is what they are.

I recently spoke with a woman who has Asperger's syndrome. She was extremely excited to be heading a campaign "on behalf of people with autism." She asked me if I could write a list of things that Billy needed, from schooling needs to his future needs. When I responded with my list, she told me that very few of the things I needed for Billy were what she, or indeed people with Asperger's syndrome, needed. In fact she failed to see the importance of much of the list I put together for Billy.

So here is the problem: people with Asperger's are able to speak up on their own behalf. People with autism cannot: we have to do that for them.

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If I asked Billy what people with autism need, he would say a Nintendo Wii in every room of every house. The Department of Health recognizes that people with autism need a voice – but please make sure that the voice that is listened to comes from the parents and caregivers who live with autism and look after people with autism who, by definition, don't have their own insights and their own voices. The parents and caregivers are the people who really know what is needed better than anyone. Please continue to give people with Asperger's their voice. In fact, we should seriously consider having a National Asperger's Society as well as a National Autism Society. I can't see how we are going to tackle these equally valid but different issues unless we do. There is no doubt that people with Asperger's and autism need support, but their needs are different – different enough for this to be a problem.

I get frustrated when I see the autism community bickering. If you stand back and look at it, it always comes down to the same thing: one part of an organization disagreeing with another part over the efficacy of their mission and their approach. Most autism charities and organizations are set up by parents and caring practitioners working hard to achieve the goals they need for their children to develop. It gets ugly when the status quo, received wisdom, or any spokesperson says, "This is how it is, and this is how it has to be"; we are compelled to fight back, fight with passion for what we need and what we believe. I believe a good starting point would be to stop putting autism and Asperger's Syndrome under the same umbrella; both are equally important, but one can't speak for the other. Both deserve their own voice.

THE AUTISM TRUST

One of the most frequent questions I am asked is, "Where are you going to build?" The answer is everywhere. We have to build centers everywhere. In order to do this, we need to form teams in every county and every state and every country to lead and manage the development of the centers. We already have teams working hard in Dorset, Suffolk, Cambridge, Scotland and Surrey here in the United Kingdom, and teams are now forming in New York, Dubai, and Columbia. The Autism Trust's vision is vital for our children's future. Unless we start now we are going to lose more teenagers and adults to futures that are simply unacceptable.

Let's look at Billy: he's 13, going on 14 (April 30th), he's going through puberty, he's taller than I am, has size 10 feet and is extremely strong. Billy has become fascinated by women – the larger the better. He has started running up to a woman he likes, grabbing her, kissing, hugging and then, the ultimate nightmare: pressing himself up against her. We are working on this, and it is getting better, but he needs to be monitored and mentored through this very difficult time. Given Billy's obvious difficulties, this may seem touchingly innocent and easy to rationalize, but it's far more

serious than some may think.

Last year I got a call from a very distressed mother who told me the story of what had happened to her son. Her boy was in his late teens, had autism and was virtually nonverbal. He had an obsession with Argos department store catalogs. One day he spotted two girls outside his house clutching the latest catalog. He ran out and tried to communicate with the girls, trying to exchange his old catalog for their new one. The girls (around 14 years old) were confused and frightened by him, ran home and told their parents about this strange man who had approached them.

To cut a long and painful story short, this man with autism is now locked up in a secure hospital, and seems unlikely to be released as he is now considered to be a "danger to society." His deeply distressed mother describes her son as a petrified young man who cannot understand why he is there. More worryingly, he has lost over half his body weight since being incarcerated.

Watching Billy hugging women anywhere he can fills me with horror and fear.

If I don't build these centers, Billy could end up in prison – not because he is bad, or perverted, or a danger to society, but because he doesn't understand society's rules and society doesn't understand him. Billy learns fast, but he needs expert guidance, careful and consistent prompting, and ongoing support.

WHY DO WE NEED RESIDENTIAL ACCOMMODATION?

I received a letter recently from a lady telling the story of her autistic sister who was living in a flat in the community "with care." This desperately sad letter tells how her sister was found in her flat 9 days after her tragic death. It had taken 9 days for anyone to find her; so where was the care? The photos enclosed with the letter were horrific; this poor woman with autism had been living in absolute squalor. It's difficult to imagine how anyone could survive in such filth and mess. If she had been given the care and support she so badly needed and was promised, then maybe she would be alive today. Aspirations, policy and targets are one thing, but, sadly the reality is so often entirely different.

The need for The Autism Trust's vision of a safe and productive future has never been as vital and urgent as it is today. We are here as a charity to make a real difference: to deliver realistic care, dedicated support and productive futures. Billy, and a great many others like him, will be safe, will be able to thrive and can put back so much into society when we give them the chance. The real question isn't why are we building the Autism Trust Centers, but what will happen to our children if we don't?

There are so many children like Billy out there, growing fast into young men and young women. Help me build The Autism Trust or we may have to be prepared to build more prisons . . .

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