**What is Neurodiversity? By Mike Stanton**

When I attended the International Autism Conference in London last year I heard Professor David Amaral tell the story of a young man with Asperger Syndrome who was visiting the MIND Institute at UC Davis. He was asked what he would do if they could develop a pill for autism. He thought for a while before replying that he would take half the pill.

I think this illustrates a real difference within the autism community. There are many who pathologize autism as a disorder that afflicts an otherwise healthy individual. If you hold this idea you naturally look to understand the causes of autism in order to find that “autism pill.”

The idea of Neurodiversity was developed by autistic people in opposition to the pathologizing model. According to them autistic people are not disordered. They have a different sort of order. Their brains are differently wired. They think differently. They do not want to be cured. They want to be understood.

This is not to deny that autistic people often face real difficulties. That is why the young man at the MIND Institute told David Amaral that he would take half the pill, but not the whole pill.

**What does Neurodiversity mean for parents?**

The cure mentality places great pressure on parents to rush into interventions. Then there is the guilt. Was there something I did or didn’t do that caused the autism in my child? Can I put it right.? How can I not put it right? Instead of raising your child you can spend all your time trying to fix him. [One mother’s story](http://www.telegraph.co.uk/health/main.jhtml?xml=/health/2006/05/08/hastor08.xml&sSheet=/health/2006/05/08/ixhmain.html) illustrates this.

*Olivia was four when Liz finally faced up to the diagnosis, wracked with guilt that, having given birth to her at the age of 42, she was somehow responsible for her child's problems, either directly or as a result of a pre-natal diagnostic test (amniocentesis) that went wrong.*

*Her way of dealing with this lonely burden was to take action. "I wanted to rip the autism out of Olivia with my bare hands," she says. In the years that followed, she whirled her daughter from one therapist to another, trying everything from cranial osteopathy and "brushing" her nerve endings, to Portage - a method of teaching everything in tiny steps.  
[…]  
"Every practitioner is convinced that his or her treatment is the one and you feel compelled to try everything to find the one that will open up your child. I have seen children who have made remarkable improvements, but I would never say they have been cured or recovered.”  
[…]  
Having reached a state of mind where, even if she could, she would not change Olivia, she tries to concentrate on the good qualities that come with autism - honesty, uncompetitiveness, absence of spite.*

Embracing Neurodiversity allows you to stop looking for a cure because there isn’t one. I agree with the [Autism Society of America](http://www.autism-society.org/site/News2?page=NewsArticle&id=8273&news_iv_ctrl=0) that,

*Most of the enlightened world knows that autism is at its root, genetic, and therefore by definition it is not something that can be considered “curable” or a “disease.”*

Giving up on a cure is not the same as giving up on your child. In fact it can help you to take a more balanced approach. It is easier to reflect on your child’s strengths as well as their difficulties and take up Lorna Wing’s advice that,

*an autistic child can only be helped if a serious attempt is made to see the world from his point of view.*

Sometimes our biggest problem lies with other people. One mother gave me permission to quote something she wrote in an email about autism and acceptance.

*I think that it's a bit insulting sometimes for people, especially family and friends, to try to give me information about how to make my son be a 'bit less autistic'. It makes me think they want a short-cut to make him more acceptable. I'd prefer it if they tried to connect with him and enjoy him as he is. Then they'd really be able to help him to progress.*

This is the essence of Neurodiversity. First accept the difference. Then find ways to work together. And it is not all about problems either. We all had a favourite subject at school that we were good at and something else we really struggled with. Imagine being told that you had to drop your best subject and have double lessons in your worst subject.

That is not so far from the experience of lots of autistic children whose interests and talents are sidelined while we concentrate on their difficulties. This can send all the wrong messages to our kids. They learn about their limitations but rarely get the chance to achieve. So they put up barriers to protect what is left of their self esteem. You try and offer constructive criticism. They take it as a mortal insult.

If we accept somebody and work with their strengths we can help them to find ways of dealing with their problems that work for them. I spent a lot of time trying to solve my son’s problems and making choices for him. The turning point came when Dave, a clinical psychologist asked him to think about what he wanted. Prior to this my son had always been encouraged to meet other people’s demands and expectations. Dave was the first person to give my son explicit permission to put his desires before our expectations.

**When does Neurodiversity give way to disability?**

It is a common mistake to believe that neurodiversity is only for people who are "high functioning" or are "mildly autistic" or any other synonym for "not my child." The argument goes that neurodiversity is all right for you. You can talk. You can write. You are intelligent. My kid is non-verbal, self-injures and needs constant care.

There is a whole set of problems that comes with being high functioning. People expect you to be normal or at least to act normal. So you expend a lot of mental energy pretending to be normal which leaves you wide open to stress related problems like depression, obsessive compulsive disorder and social anxiety disorder. You may be paralyzed by panic attacks or have uncontrollable bouts of anger. This can get you in trouble with the law or trapped in the psychiatric system. Being high functioning is not a soft option.

Does the demand for tolerance and understanding mean ignoring children in distress, doing nothing about autism, denying the need for scientific research? Of course not. We support the need for decent peer reviewed research into the problems associated with autism. It is by no means clear what constitutes the core features that are fundamental to autism, and what are secondary factors. We just do not see any justification for seeing all a child's problems as being down to its autism and imagining that there is a magic bullet to solve them all.

**Who will speak for my child?**

This is a real concern, especially for parents of children who are highly dependent on others. But we are all mortal and when we die who will speak for our children then? Neurodiversity is a way of thinking about human difference that has the potential to change the world for autistic people in ways that are comparable to the impact of the liberation movements for women, blacks and gays. When society speaks for my child, then I can die happy.

The National Autistic Society in the UK recently changed its constitution. We are no longer a parent led organization. Previously there had to be a majority of parents elected to our National Council. Now there has to be a majority of family members - parents, siblings and **people with autism.** Many parents of severely autistic children were worried that this dilution of control would weaken their voice as the only effective advocates for their children. Some were worried that high functioning autistics would take over the NAS and their children would be forgotten.

I pointed out at the AGM that in my experience autistic people who were willing and able to campaign and hold office were concerned for the rights of all autistic people. They take Neurodiversity seriously and value everyone on the autistic spectrum. The parents of children with Asperger Syndrome were far more likely to push the NAS down the path of providing mainstream support for their children at the expense of those who needed more expensive care and protection.

Neurodiversity, like freedom, is indivisible. And its benefits are being seen within the NAS as the professionals in our care homes and schools strive to create mechanisms whereby all autistic people within our structures are able to self-advocate, make choices and exercise personal autonomy.

**What does Neurodiversity mean for professionals?**

By listening to autistic adults I have changed my practise in relation to the autistic children with severe learning difficulties in the special school where I teach. I no longer expect eye contact. Instead of demanding, "Look at me when I am talking to you!" I ask, "Are you listening?" When I speak to a child I give them extra time to process my words and formulate a response. If someone is acting strangely, instead of stepping in to prevent the behaviour I ask myself, "Why is he doing that?"  
OK I am only human. sometimes I have bad days. I make mistakes. I mess up. So do the kids in my class. They make allowances for me. I make allowances for them. Some people do not get it. They think I am "letting them get away with it." Yes, like they are being autistic on purpose.

The most important thing a professional can do is to help a person understand and accept that they are autistic and then decide what they are going to do about it. A lot of autistic people spend a lot of time trying to change themselves to fit in with the world as it is. It is important for autistic people to learn how to get by in this world. But they will not do that if we try to manage the way they think. I often say that we should not teach autistic people to manage their behaviour. we should teach them to manage ours. And between us we may make the world a bit more manageable for all of us.

**What does Neurodiversity mean for autistic people?**

I am a parent and a professional. I am not autistic and therefore would not presume to speak for autistic people. There are many who can speak for themselves. You can find a really good sample at the [Autism Hub](http://www.autism-hub.co.uk/), a place where autistic people, parents and professionals meet with no distinction and anyone is welcome providing you share our respect for the condition of being autistic. We seek no fundamental alteration to this state of being but we do seek to intervene sometimes should the situation require it. And when we do intervene we should remember the words of a very wise person with autism, my son.

*My autism is not a problem. It creates problems. But it is not going to go away. I want help with my problems not with who I am. I want you to offer support but do not try and change me into someone else.*

Links

One mother’s story

<http://www.telegraph.co.uk/health/main.jhtml?xml=/health/2006/05/08/hastor08.xml&sSheet=/health/2006/05/08/ixhmain.html>

Autism Society of America

<http://www.autism-society.org/site/News2?page=NewsArticle&id=8273&news_iv_ctrl=0>

Autism Hub

<http://www.autism-hub.co.uk/>

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