

## **Reflections on diagnosing autism spectrum disorders**

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## **DISABILITY & SOCIETY**

### **CURRENT ISSUES**

#### ***Reflections on Diagnosing Autism Spectrum Disorders***

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I was recently in America to observe how world-renowned teams approach the process of diagnosing autism spectrum disorders (ASDs). As a teacher and a Senior Lecturer in Autism I have been aware for many years of how parents have often struggled to obtain a diagnosis of autism for a child. I have upheld the position that a diagnosis of ASD leads to a better understanding of 'the problem' and acts as a signpost to appropriate mechanisms of support. Recently, however, I have begun to question my total allegiance to the dictat that a diagnosis of ASD is helpful.

I am currently undertaking a doctoral study into the impact on parents when, unexpectedly, their child is given a diagnosis of ASD. Mostly, the parents have been looking for practical support in developing their child's language skills and have not

anticipated ASD. In three cases I have been researching in depth, the diagnosis of ASD has had a largely devastating impact on the parents, disempowering them by causing them to question their ability to interact with and provide for their child without specialist training, even though they were doing an excellent job up to the time of diagnosis. The term 'Autistic Spectrum Disorder' causes them to rethink completely their child's potential future, making them fearful of what lies ahead. Through talking with others and through their reading, the parents become unsure of how their child will be in the future; one family who had a very co-operative young son began to become highly anxious that he would, in the future, develop severely non-cooperative behaviours like children they read about in textbooks. I have seen that the label becomes more significant than the nature of the child. I even found myself recently describing children, from a photograph, to a friend as; 'this is the one with ADHD, this is Sally and this is Jane who has Asperger Syndrome'. Only the child without a diagnostic label was defined simply by her name.

Many of these concerns with labelling I discussed with colleagues from the UK travelling with me on my trip to the US. Two of those colleagues are proponents of the social model of disability and interpreted my comments as evidence of how diagnostic labels can 'pathologise' a child and promote the danger of segregating them from mainstream society. What I believed to be a positive, indeed an essential requirement for support of children and their families, that of an accurate medical diagnosis, appeared to be perceived by them as something to be avoided at all costs.

It was in this context that I arrived to observe approaches to the diagnosis of ASDs at clinics in the US. The practice I observed was well defined and clearly articulated. The practitioners I met see it as vital to identify for each child a matrix of ability which identifies strengths, difficulties and learning style. In my UK based research parents regret the absence, within the diagnostic process, of a balanced emphasis on their child's strengths as well as difficulties. They often perceive professionals as only being focused on what their child cannot do. In US clinics I visited, the emphasis was firmly on identifying the child's abilities and areas for development rather than in just naming a condition. However, the US system does force professionals to 'diagnose and label' as it is this which determines the allocation of support resources to the child. Certainly in North California, children with a diagnosis of autism rather than the more general title of 'mental retardation', receive much greater funding so diagnosticians can be put under pressure by interested parties to come up with the label of 'autism' wherever possible. Families within my UK based study experience this exact same problem of resource allocation being label-led. Parents I talk to, who say they want practical help from an autism-specialist team, soon come to realise that professionals in such a team can only help those parents whose children have a diagnosis of ASD. From the parents' perspective, if they want the advice, then they would first have to accept the imposition of the label; parents report that they feel 'blackmailed' into diagnosis.

On observing diagnostic sessions within the US I was impressed by the commitment of the team to the children and parents they were working with. Their warmth and affection for the children was immediately evident as was their care and concern for the parents. I felt the parents' tension keenly as they awaited pronouncement on their child,

as though the opinion of the professionals could actually change their child's identity and determine what their future development will be. I became as aware of the parents' agendas surrounding diagnosis as of what it could mean for their child. This reminded me of something Michael Rutter (*personal communication*) once told me, when he was running diagnostic clinics at the Maudsley Hospital in London; *'it is always important to bear in mind who is referring this child and why now'*.

Parents usually will have expectations of what engaging with the diagnostic process will provide for them. They might hope to have anxieties and fears allayed; to obtain a label, to prove to others that they were right to have concerns over their child; to receive advice on how to support their child or to find a means by which they can access additional resources. The time of diagnosis can be important as it may reflect a change in a parent's situation. The onset of depression, for example, can make a child's behaviour seem much harder to tolerate or lead to feelings that the child is unable to love the parent. A parent may be seeking placement in a particular school that requires a specific diagnosis. I remember one mother who was seeking a diagnosis of severe learning difficulties for her second son, who was showing no signs of these at his mainstream school. She simply wanted him to attend the same special school as his brother who did have the diagnosis as this provided an answer to the very real problem of needing to walk one child to school while waiting for a bus for the other.

The diagnostic sessions I witnessed recently in the US, raised many questions for me about the purposes of diagnosis and prompted a considerable step change in my own thinking. The professional approach I observed focussed on identifying what a child can

do; what areas of difficulty they are experiencing; devising strategies for support and considering the most appropriate educational provision which will suit their individual profile. Although it is essential to build up a picture of how individuals learn, in order to know how to teach, I also recognise the importance now of dual foci; as well as understanding the impact on the individual it is essential to identify what *everyone else* needs to do; what areas of difficulty others in the child's life are experiencing (including professionals) and what support *others* need. This latter focus would, for example, shift emphasis towards working out the most appropriate responses a child's local school can make to suit the child's individual profile. For a hard-pressed parent this would immediately remove the '*how to get child A on the bus and simultaneously walk child B to school*' dilemma such as typifies the sort of practical problem that leaves parents with segregated children feeling they can barely cope.

A major feature of good practice I saw in the US was reflected in the individuality of a child always being regarded as paramount. Children were not viewed as the product of autism; personality, inherited characteristics and life experience were all considered when deciding how the child is perceiving the world. Comments made to a mother such as '*he is probably going to be quiet like you while his brother will be louder, more like his dad and that's no bad thing*' served as a reminder that not every behaviour need be interpreted as a sign of 'deviant development'. A child's skills and difficulties, or as I prefer to term them, 'areas of challenge', were identified through parental accounts and standardised tools of assessment. But I came to realise that these 'areas of challenge' are consistently being interpreted as '*areas of challenge presented by the child*'. It occurs to me now that there is much to be learned from identifying '*areas of challenge for*

*parents and professionals* – and further, what difference to outcomes for a child could be made by identifying ‘areas of challenge’ through the child’s own accounts?

At present, results gleaned through the standard assessment tasks and parent interviews in the clinics I visited are evaluated by an Assessment Panel and a diagnosis is given to parents before they leave the clinic. Many families travel significant distances to attend a clinic so it is seen as important to reach a diagnostic decision in a single visit. Parents wait in another room while the panel discuss the case and make their evaluation. The convening of diagnostic panel members behind closed doors to reach agreement, is common practice in my experience, but my ongoing research suggests this is problematic. I have found parents perceive professionals as ‘colluding’ in the eventual diagnosis and believe individual panel members are influenced in their decision making by other professionals on the panel so that an ‘agreed’ position can be presented. Parents say, however, that they feel able to accept that professionals hold different views and would prefer to be engaged in an open process where they can understand how the diagnosis is reached and thus achieve a more trusted outcome (see also Dunn and Moore, 2004). Involving parents in the process of reaching a diagnosis is crucial if parents are not to feel cast to one side while others reach conclusions on their child. Involvement in reaching a diagnosis also reduces the opportunity for misinterpretation. While parents anxiously awaited the results of an Assessment Panel following a session I recently took part in, they heard the assembled professionals laughing. Although this was over unrelated matters the parents may well have believed the laughter to be about them and their child. I realise that involving parents in all aspects of discussion will present professionals with some challenges but find myself concluding that these must

be surmounted and are preferable to parents experiencing a loss of control in relation to their child. Practice in clinics I observed was undoubtedly built upon a premise of respect, yet I have become increasingly worried about how easily this respect can be compromised. Parents in one clinic, for example, walk with their child past a door labelled '*Pervasive Developmental Disorder Laboratory*' which seems to me to identify a reception marked by inadequate consideration and respect.

During the course of my recent visits I became increasingly uncomfortable with the extent to which giving diagnostic labels reinforces a system of provision that is about recycling the potency of professionals and the impotency of parents in the lives of vulnerable children. Within current UK and US practice I have seen, labels are frequently required to enable access to specialist funding which sets the child on the road to specialist - and mostly segregated - provision and ultimately moving towards an excluded future. In one US clinic with a reputation for '*telling it like it is*'; parents are told the exact results of diagnostic tests and a clear prognosis is given by professionals in response to the often asked question, '*what will my child be like when they get older?*'. Children themselves rarely have a determining role in prescribing their futures and the voices of parents are frequently marginalized.

Trying to make sense of multiple confusions which have now crept in to my thinking on the role of diagnosis in the lives of children with autism I recall a warning given by Elizabeth Newson at a conference some years ago, that to view autism simply as '*an alternative way of being*' could be to minimise the pervasive and devastating impact that it can have on the individual and their family. In addition, I am increasingly open to

the possibility that to view autism simply as an alternative way of being could be to minimise the pervasive and devastating impact that that *an inadequate response by other people* can have on the child and their family. As a professional I feel caught between wanting to acknowledge all the positives around having a child, to celebrate the gift of a child with autism in the same way as an other child's life is celebrated – and on the other hand recognising that there is a harsh reality to parenting a child with an ASD. If parents find themselves in an isolated twenty-four hour struggle, largely unsupported by appropriate services I accept it is the lack of support that causes disabling problems and it is not simply impairment that creates problems. Yet within current funding strictures I cannot be optimistic that the level of service provision will increase unless the amount of stress on the individual and the family is emphasised through a formal diagnosis of ASD.

While in the US I visited an organisation called *Parents Helping Parents* ([www.php.com](http://www.php.com)). This group is parent led and supports the families of children with a range of impairments. The group recognises that when a child is born with an obvious impairment, focus is on the impairment rather than the child. To remedy this, the group members send all new parents who are referred to them a beautiful item of handmade baby clothing to move emphasis back on to celebrating the birth of a new born; a reminder that the simplest of gestures can carry a powerful – and enabling - message.

I hope that as we progress towards a more inclusive society that labels will become redundant. Through recent exchanges, I have observed ways in which my own practice can be rethought to assist in the process of dismantling the disabling consequences of

insistence on professional diagnosis. Perhaps parents will always wish to explore the origins and nature of a child's impairment but I hope that through changing the focus of my own work I can begin to offer support through developing easily accessible and comprehensive services, so that parents will be able to focus just on enjoying their child and that Jane can be Jane and not 'Asperger Syndrome'.

One of the parents in my doctoral research study mourned the loss of enjoyment of a year of her son's life, from ages 3-4 years, as attention became focused on his impairment rather than on him. The mother described this as though professionals had taken her child away from her and felt he had only 'come back' when she and her husband could see 'Sam' again, rather than the 'autistic child':

*['the autistic child'] wasn't the child I knew and now I'm just glad I've got Sam back. That's how I feel, I've just got the child back I always had. I'm perfectly happy again. But that day [when we were told he was 'autistic'] I felt like somebody had taken him away. That's the only way I can describe it'.*

Mother of Sam

Gillman et al. (2000) urge that professionals should evaluate the impact of a diagnosis on a child and his/her family and only give it if it facilitates access to resources. What I feel we need to move further towards, however, is resources allocated to entitlement rather than label. It should not be a label that determines support but a child's individual aspirations and entitlements. I wish now to promote this through critical and constant reflection on my own practice – and to start with insistence on referring to children only by name.

## References

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