When is a syndrome no longer a syndrome?

Earlier this year Asperger’s syndrome was dropped as a diagnosis by the American Psychiatric Association. What does it mean for people who were diagnosed with Asperger’s?

In national school Robert Savage struggled to make and keep friends and his one big interest in life was the TV series The Simpsons. His parents, Peter and Mary, had sensed there was something different about their middle son of three boys from the age of three but it was another six years before he was diagnosed as having Asperger’s syndrome (also referred to as “high-functioning autism”). It is a developmental disorder among people with average to high IQ that is characterised by difficulties with social interaction and preoccupation with special interests. Like any parents plunged into the world of special needs, it was a steep learning curve for the Savages but Mary recalls her GP reassuring them that if Robert had parents who looked out for him, everything would work out. And so it has.

They waited until Robert was 12 to explain to him that he had Asperger’s. Some time later, Mary remembers asking him did he mind. “He said, ‘Mum, it is like having brown eyes.’”

Aspire also fears it may lead to the loss of a diagnosis, without which children will not get support services.

While Asperger’s syndrome still exists as a standalone condition in the World Health Organisation’s diagnostic tool, the International Classification of Diseases, that is also due for revision, in two years’ time. “We are afraid it might be dropped by them too,” he says.

A two-day international conference to debate these changes in the diagnosis of autism is being held in Trinity College Dublin this Friday and Saturday. Aspire and TCD’s School of Education, the Challenging DSM-5 seminar will include the launch of “ground-breaking results” from a 10-year TCD study into the use of drama to develop the social skills of young people with Asperger’s syndrome (see sidebar).

Although there has never been a full-scale prevalence study, Aspire estimates that about 15,000 people in Ireland are affected by Asperger’s syndrome. The total autism spectrum covers about 1 per cent of the population or approximately 45,000 people in this country.

McKernan, whose son was diagnosed with the condition at age 22 in the mid-1990s, says: “They [people with Asperger’s syndrome] can’t put their feet in the shoes of other people and understand where they are coming from. The might have a special interest but they will go on for hours talking about something like train engines and not realising the other person is bored out of their brains.”

But this single-mindedness can also be of huge benefit to society, he points out. “They stick at a task when most people would have given up.”

It is suggested that Einstein may have had Asperger’s syndrome and psychiatrist Dr Michael Fitzgerald has written books arguing that famous Irish people such as W.B. Yeats and Samuel Beckett may have had it too.

Dr Louise Gallagher, professor in child

Negotiating secondary school
With the help of an “excellent” resource teacher at The High School, near their home in Rathgar, Dublin, Robert successfully negotiated secondary school. Now, aged 21, he is in his third year at the Dublin Institute of Technology in Kevin Street, Dublin, studying Electrical Services Engineering and everything is, he says, “pottering along nicely”.

He finds fitting into college life easier because “we’re all grown-ups” and recalls how, during second year, the college’s disability officer visited the class. “Asperger’s was one of the things she talked about and I told everyone I had Asperger’s. They applauded me and thought what I did was extremely brave.”

So it was disconcerting, to say the least, when earlier this year Asperger’s syndrome was dropped as a diagnosis from the new edition of the highly influential Diagnostic and Statistical Manual of Mental Disorders, known as DSM-5 for short.

Published by the American Psychiatric Association, it directs that people who would have previously been diagnosed with Asperger’s should now come under the label of “autism spectrum disorder” (ASD).

“They are saying it does not exist because it doesn’t fit their template,” says Robert. “I feel like it is a bit weird. I have known that this is who I am for so long and then someone says, ‘no that’s not it, you’re this’. I think I know myself – this is what I am.”

Mary thinks “it’s crazy” – an opinion undoubtedly shared by fellow parents, many of whom are “puzzled and upset” by the decision, according to Des McKernan, a founding member of the Asperger Syndrome Association of Ireland (Aspire).

‘Loss of identity’
For adults with the condition, “it is almost like a loss of identity”, he explains. “It is like being no longer able to call yourself Irish but having to call yourself European.”

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and adolescent psychiatry at TCD and consultant psychiatrist with a special interest in autism with the HSE, understands where the DSM-5 decision is coming from but acknowledges the anxiety it is causing, “Imagine your loved one was diagnosed with something and then you’re told that diagnosis doesn’t exist any more. If it doesn’t exist any more, then what do they have?”

One of the reasons Asperger’s syndrome was dropped was because there had been a long-running debate about what really made it stand apart from autism spectrum disorder, she explains. “There was no really robust data which showed there were any specific clinical characteristics that really differentiated the two.”

Personally, she finds it a “clinically useful” diagnosis. If another psychiatrist is asking her about a child with Asperger’s, she instantly knows what type of child is being talked about.

However, she thinks the specific diagnosis has been “less useful as a concept in terms of helping us understand what causes autism or what the underlying neurobiology might be, or in helping us towards improved treatment; by that I mean bio-medical treatment as opposed to psychological interventions that are used to ameliorate some of the symptoms.”

Different classification
It is not true to say there is no such thing as Asperger’s syndrome any more, she explains, because people with it will be classified as having an autism spectrum disorder under DSM-5.

And she does not believe, based on data she has seen, that the move will result in such people ending up with no diagnosis. “But – and there is always a caveat – every time there is a revision to the classification system, things change and we will have to re-evaluate this retrospectively.”

However, she thinks children in one of the other sub-categories that has been absorbed into the autism spectrum disorder, namely “pervasive developmental disorder not otherwise specified” (known as PDD-NOS), may now drop out of the autism diagnosis. “Personally speaking, I don’t think it is going to impact on Asperger kids as much as PDD-NOS kids.” But, with services in Ireland so “diagnosis-driven”, she understands how fearful parents are of losing resources for their children.

“Health and education services have got to move away from using diagnoses as a way of understanding children’s needs,” she argues. “It’s not useful and drives services in a particular direction that doesn’t work for the clinicians and doesn’t work for the families or the children.”

A clinician who wants to make sure that a child has access to a service has to fit him or her into a diagnostic box. “That happens all over the world, not just in Ireland. In California there has been a huge rise in the prevalence of autism, probably due to exactly that.”

Helping a family
Whereas Gallagher sees a diagnosis as much more about helping a family to understand the needs of the child. “If I was talking to a family, I would still use the term Asperger’s syndrome because I know that family will go away and access material from the internet, where they will find information that is very relevant to them and their child.” However, she adds, if she were giving a diagnosis for the purposes of resource, “I will probably stick to DSM-5, as that is what I am expected to do”.

Robert has been involved with the TCD drama programme from the beginning and it has helped him develop coping mechanisms. It also gave him, he says, “the biggest break I had with socialising”.

In 2009, when the X-Men Origins: Wolverine film came out, he found out that another guy in the group had a “decent interest in comics like I did and we both agreed that the film was stupid on so many levels”.

Somebody else joined in the conversation, they bonded over their mutual interest and now there’s a group of four friends who socialise together regularly.

“It is the social niceties that Robert is not great at,” says Mary. He finds it hard to remember details about people so as to bring them up in conversation when they meet again.

Social challenges
Robert reckons he knows the names of about three of the people he has been in college with since first year, and that is only because he worked on assignments with them. “The rest he has not talked to, or only in passing about topics such as the weather or politics.”

He thinks he might appear rude if he asks them their names but then “a few weeks ago somebody said: ‘Do you even know this guy’s name?’ It was an awkward moment, I will admit,” he laughs.

However, despite the challenges of socialising, Robert is not unhappy or frustrated with life. “I am content,” he says simply and, as Mary is quick to point out: “That is a gift in itself.”

For more information see aspire.ie
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‘These are people’s lives. They are not just a diagnosis or label’

"Ground-breaking" research at Trinity College into "sub-types" within high-functioning autism is to be presented at this week’s conference in Dublin on the changes in diagnosis.

It was an unexpected revelation in a project that started 10 years ago to explore if educational drama could be used to help people with Asperger’s syndrome to improve their social skills.

As researchers closely monitored the progress of the young people attending weekly drama sessions devised by the head of TCD’s School of Education, Dr Carmel O’Sullivan, they began to see very definite patterns of behaviours, which could be classified into sub-types.

By observing biological and behavioural markers among the young people – ranging from the colour of their hair and eyes, their gait and the way they sat in a chair – they began to be able to predict how they would respond to all sorts of scenarios, such as a person sitting beside them, people making a noise, other sensory stimuli and teachers using a certain tone of voice.

"For us it was quite fascinating to watch because not only did it allow us to understand the lives, the realities and the engagement of the young people much better, it helped us in the teaching," says O’Sullivan.

She worked out her first system of classification in 2010. "Since then I have been testing and refining it to fairly robust categories where we are confident now in putting this out to the wider world."

The 12 sub-types identified include those "holding court" – they are almost like showmen, she explains. "You have the 'coasters' who will go along by the wall quietly and draw no attention to themselves and the 'Bapes', standing for Busy, Active and Physical Externalisation – there is a lot of flapping, a lot of muttering going on."

There are 33 different characteristics which they now monitor. "It provides almost an inventory as a diagnostic tool." It’s a "phenomenally powerful resource", she believes, because once parents and professionals know which sub-type they are dealing with they can tailor their approach for much more effective relationships and results with the young people.

She describes it as a very finely tuned, pedagogical instrument. "So if you have one of these sub-groups you should do this and not that, and they are quite radically different from each other."

Aside from the discovery of identifiable sub-types, the other strand of the research is that O’Sullivan calls the Social Drama Method, has come up with very positive results. They show "medium to large" effects on the 100-plus participants across the board.

"There have been considerable improvements in things like their anxiety levels, their ability to withstand body contact, in their problem-solving ability, in the development of empathy and in initiation of interaction."

Another surprise was that the improvements did not plateau out, as they would have expected.

"They can continue to make improvements if the interventions are properly targeted to their needs," says O’Sullivan, who hopes that this week’s presentation will attract both national and international attention and encourage other researchers to investigate further the science of their findings.

While focusing on sub-types appears to be at odds with the move by DSM-5 to introduce the umbrella term of autism spectrum disorder, she believes its ultimate goal is to understand the different subgroups.

"I think what they were trying to do with the DSM-5 was look at the samples all together and see what’s common and what’s not – pull them together in the first instance and see where the subtypes happen within that."

However, she hears the young people with Asperger’s syndrome asking does this mean that they now have autism?

"What they are picking up on is the more traditional, negative associations, that autism is more severe," she points out.

"We have to take that seriously because these are people’s lives. They are not just a diagnosis or label."

The two-day conference, Challenging DSM-5, is to be held in Trinity College Dublin this Friday and Saturday (November 8th and 9th). See challengingdsm5.org
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