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Diagnosing Asperger Syndrome

Sunday, July 05, 2009 By Martha Kearns

When Robert Savage was three years old, his parents knew that something was not quite right.

He did not seem to be listening to them, but fears that he might be deaf were quickly ruled out by doctors.

It was when Robert was seven years old that his primary school principal called his parents, Mary and Peter, and said she thought there was something amiss. She told them they had two options: waiting further to see how he developed or taking him to a professional.

"We knew in our heart of hearts that something was wrong, so we went to get help," said Mary.

First stop was a child psychologist who did not know what was wrong and referred them to an Eastern Health Board speech and language therapist.

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"We spent a long time with her before she said that he did not have a speech problem and she advised that we go to our own GP."

Their GP referred them to a child psychiatrist in Our Lady's Hospital for Sick Children, Crumlin, who referred them to the Lucena Clinic, a child and adolescent mental health service, near their home in Rathgar, south Dublin. It was there, at aged 9, that Robert was finally diagnosed as having Asperger Syndrome.

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The Savages' story is fairly typical of the lengths to which parents who have children with Asperger Syndrome (AS) have to go to have them diagnosed. One of the problems with AS is that it is a hidden condition and many of those who have it are never diagnosed.

"This can cause problems in the workplace as well, as the individual can be seen as distant, rude or aggressive at times. When people don't understand the reasons behind their behaviour, it can seem as if they are behaving differently just for the sake of it," said Dr Carmel O'Sullivan of Trinity College Dublin. "The syndrome needs to be diagnosed, understood and valued."

According to the Asperger Syndrome Association of Ireland (Aspire), set up by parents in 1995, the lack of services and delays in getting diagnoses have placed enormous burdens on parents.

"For many, obtaining a diagnosis is often a major undertaking and can take up to several years, as the waiting lists are so long. A lot have to go privately to get assessed," said Aspire's development coordinator, Shane O'Halloran. "Even with a diagnosis, parents soon realise that few primary and secondary schools have the staff or resources to deal with the special needs of children with AS.

"It normally falls back on the parents to pick up the pieces. There can often be knock-on effects for the mental health of the parents, because they have to do so much on their own," said O'Halloran.

It is estimated that between 1 and 3 per cent of the Irish population has AS, with about nine times as many males affected as females. AS is an autism-spectrum disorder, but most of those affected have an average or high IQ and often can be extremely gifted in their chosen field - some people believe that WB Yeats, Albert Einstein and Isaac Newton had the syndrome.

The main symptom of AS is that the person with the condition has major problems with social interaction and communications skills.

"People with Asperger Syndrome do not see the world from the same point of view as everyone else. This is not a choice for them. It is an inability to see and understand the world from someone else's shoes," said O'Sullivan, who is director of postgraduate teaching and learning at TCD's School of Education.

"If we try and encourage change and flexibility in their daily routines without preparation, a person could react defensively and negatively to being placed outside their comfort zone. But if we give them appropriate support and educate both the person with AS and those around them about the condition, they can live a rewarding life."

O'Sullivan has been spearheading ground-breaking research at TCD which uses drama in education to help young people with AS. More than 60 people between the ages of six and 21 have participated in the project, which is the only one of its kind in the world, since it started in September 2004.

Drama in education classes at TCD create a safe environment for the young people to test their social skills, help their emotional education and increase their ability to empathise with other people.

Initial research findings have found it to be successful, particularly in building the young people's self-confidence, imagination and the development of drama skills.

The first phase of the project is ending this month and culminates on Wednesday, with the launch of a new educational resource DVD, which will give parents, teachers and young people a practical guide to dealing with the syndrome. Produced by TCD and Aspire, the DVD will be launched by Minister for Education and Science Batt O'Keefe and the Provost of Trinity, Dr John Hegarty.

The Department of Education and Science will distribute it to teachers in all primary and secondary schools, as well as to parents, professionals and others working with those with AS.

To date, €250,000 has been allocated to fund the running of the classes, and additional

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funding is now being sought to roll out the project nationally. It is also hoped that the second phase will involve training teachers and other key personnel so the approach can be used in mainstream schools.

"Raising awareness about the condition is an important outcome of the first phase of the project. Now we want to bring the intervention to more people. No one else is doing an intervention like this in the way we are here in Trinity, and we hope that we could roll that out nationally. But in the current climate, we don't know if the money is there," said O'Sullivan.

The success of intervention is evident in Robert's case, whose life improved once he received the diagnosis and started attending the TCD classes. However, it was not all plain sailing. When Robert went into second-level education at the High School in Rathgar, which has 770 students, he had major problems being around so many other children.

"Every morning, he used to have to go to the resource room and pick staples off a stack of staples, one by one, before dropping them individually into a 7-Up can. He had to do this until he calmed himself down enough to go to class. He had to be calmed down in other ways such as being taken out of class and being wrapped in a duvet," said his mother, Mary.

"Things have changed since then. He sang a song in front of 300 children at a school concert to raise money for charity and gave a talk at a horseriding school's agm. He also now has a little network of friends and he volunteers once a week at the Oxfam shop in Rathmines. This is a long way from someone who had to pick off staples before he could face a group of people."

Mary puts Robert's progress down to the help he is getting at the classes in Trinity and from his own school, which she said was "phenomenal". Now 17, Robert - who has an intense interest in Marvel comics - has just finished fifth year and will sit his Leaving Certificate alongside his classmates in the High School.

Sean Leaney, 15, from Glasnevin in north Dublin, was one of the first to attend the classes at TCD and, as a result, has dramatically improved his social skills. "Navigating the social problems is huge and it has massive knock-on effects in terms of relationships and friendships. The classes have been very positive with this," said his mother, Veronica.

When Sean was leaving Montessori school, his teacher warned Veronica and her husband, Ronan, that they were going to have problems in primary school.

"He didn't mix with children and spent a lot of time on his own. He wasn't settling at all and was causing disruption," said Veronica, who has one other child, Fiona, 14.

When he was five years old, his parents took him to a psychologist who told them his problems settling down were normal when a child was very bright. It took three and a half years going from health board clinics to private clinicians before he was diagnosed with AS.

"Sometimes I felt so tired, it was like talking to a brick wall. No one will be a child's advocate like their parents. You see it with all the parents, you have to be proactive and dig your heels in. If a child has an obvious visible problem, it is easier to get help. When they have something like AS, which tends to be a slow burner and doesn't expose itself immediately, it can be hard to get help.

"There was a lot of reluctance to diagnose. I think people are reluctant to put a label on someone. But I feel it is better to have a label on them and be in the system where they can get help, rather than be outside it," said Veronica.

Meanwhile, Mary Savage's hopes for Robert are the same as any mother has for her child. "After third-level education, I would love to see Robert living in an apartment, looking after himself. I also hope he will marry because he is a good, honest, decent, loving - and handsome - person."

This scenario is not always possible for everyone, mainly because of the lack of services. Many have parents who cannot fight for them, either from a lack of interest, knowledge or finance.

"I fought tooth and nail for that kid. It's awful to say, but the only people you see getting help are middleclass people. You don't see inner city children getting help because if you don't have the money or the know-how, no one wants to know," said Mary.

"If there is no intervention there, kids are just going to end up in prisons or mental institutions - places that they should not be. Anyone can improve and be taught how to live with AS - if they are only given the chance."

What is Asperger Syndrome?

While Aspergers is an autism spectrum disorder (ASD), it differs from other forms of autism. Those with the syndrome usually have an IQ within the normal or high range, but have extremely poor social and communications skills.

According to the Asperger Syndrome Association of Ireland (Aspire), common characteristics can be an inability to form relationships, one-sided conversations and an intense absorption with a special interest.

They also find it difficult to empathise and identify with others, which is believed to stem from their inability to read emotions in others. As a result of this, they can often experience bullying and be isolated. Sometimes the movements of those who have Asperger Syndrome (AS) can be clumsy and they can be inflexible in their thinking.

"However, with the proper support, people with AS can lead full and productive lives," according to Aspire.

The syndrome was named after the Austrian paediatrician, Hans Asperger, who, in 1944, identified children he was caring for as having a particular disorder.

While the children had normal intelligence and language development, they were lacking nonverbal communication skills, demonstrating limited empathy with their peers and were physically clumsy. In 1981, the condition came to be known as Asperger Syndrome. The disorder can range from mild to severe. There is no known treatment that has any effect on the basic impairments underlying AS, but difficulties can be diminished through appropriate management and education.

Visit www.aspire-irl.org for further information on how to identify if your child has AS.

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