

AUTISM IN CHILDREN

THE HIDDEN DISABILITY

Hollywood stars Dustin Hoffman and Tom Cruise in their multi-award winning film, *Rain Man*, opened a window on the world of autism back in 1988. Today, in 2012, it needs to be pushed open even wider. **Words by Jenny Sims**

Did you know?

One in 100 children are diagnosed with autism.

The tale of two brothers, Hoffman playing Raymond - an autistic savant, was criticised for perpetuating a false media stereotype of people on the autistic spectrum. But it was also praised for dispelling misconceptions, improving public awareness and exposing the failures of healthcare and other services.

“Autism is a serious, **lifelong developmental disability** that affects how a person communicates with, and relates to, other people.”

Life for autistic people and their families has undoubtedly improved since *Rain Man* was first screened. But myths about the condition still abound, public awareness still needs raising, and support services are still in short supply.

Ironically, in the film script, because of Raymond, his selfish self-absorbed brother Charlie Babbitt becomes a better person. In real life, that can happen too, as Heather Wildsmith's children can attest (see case study), but the extent of the impact on the whole family can be devastating. And the hardest times are often the bewildering years before the person with autism gets a diagnosis.

WHAT IS AUTISM?*

Autism is a serious, lifelong ►

developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with the syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.*

FACTS ABOUT CHILDREN WITH AUTISM

- One in 100 children in the UK are diagnosed, but the incidence is probably much higher because many children are undiagnosed, and there is no central register.

“Currently, the average age of children receiving a diagnosis of autism is six, and 12 for Asperger syndrome.”

- Over 40 per cent are bullied at school.
- Over 50 per cent are not in the kind of school their parents believe would best support them.
- One in five has been excluded from school, many more than once.
- They can be very good at learning facts, skills and talents.
- They tend to be very honest, and if communication skills develop, report

things very accurately and openly.

- Autism can be a hidden disability, you don't always know if someone has it.
- It affects more boys than girls, possibly because of genetic differences between the sexes.
- There is no cure, but the right support can transform lives.

WHEN AND HOW TO SEEK HELP

‘The key thing is getting a diagnosis – and as early as possible – once people have got that they can get access to the relevant support,’ says Dr Judith Gould, director and co-founder of the Lorna Wing Centre for Autism*, a specialist diagnostic and assessment service in Bromley, Kent, for people with complex difficulties.

Currently, the average age of children receiving a diagnosis of autism is six, and 12 for Asperger syndrome. ‘That’s still quite late to be without any support in place, especially for Asperger’s’ said Dr Gould.

Early clues to autism can be found in babies and toddlers. ‘For example, babies like to look at people and at other babies. If they’re not interested it’s a little sign. Delayed development

in walking and talking are other signs,’ says Dr Gould.

If children are not using their first words by the age of 18 months to two years, parents should start sharing their concerns with their health visitor. Next they should get a referral from their GP to a child development specialist or paediatrician.

But Dr Gould acknowledges, awareness about autism has improved since she helped set up her clinic 21



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*National Autistic Society (NAS) definition

years ago, but the provision of services is still patchy – depending on where you live. She always tells other health professionals to ‘listen to parents’.

‘Parents know best instinctively a child is different or if something is wrong,’ she says. For example, if children don’t mix with other children

in playgroup and if they don’t want to interact, ‘alarm bells should ring’ says Dr Gould.

Because children with autism are different, they often have major problems with bullying when they become teenagers. ‘It’s particularly awful for teenage girls who get picked on and targeted on Facebook and

Twitter’ said Dr Gould.

She added, ‘Unfortunately autistic girls are less likely to get a diagnosis than boys because superficially girls are more sociable, they are generally quiet and don’t cause trouble. Boys with autism can be boisterous, which is a clue which can be picked up by teachers.’

For further information, contact National Autistic Society, www.autism.org.uk 0800 800 4104. The NAS Lorna Wing Centre for Autism Tel: 020 8466 0098 Email: lornawingcentre@nas.org.uk. Autism Action UK www.autismactionuk.co.uk/ Facebook-Twitter. National Institute for Clinical Excellence guidance on autism www.nice.org.uk

Case Study

LIVING WITH AUTISM

Thomas Wildsmith, now 16, was “lucky” to be diagnosed when he was four with “social communications disorder” - as autism was then known.

His mother, Heather Wildsmith, London & South East Area Development Officer for the National Autistic Society, says he was born perfectly normal, and had two normal older siblings – a sister, then 14, and brother, 11. But at four months Thomas contracted viral meningitis. It left him with epilepsy and developmental delays, and aged four, he had no words at all.

Heather recalls, ‘When you first get that diagnosis you grieve for the child you thought you had.’

But it meant he was able to receive speech and language therapy early. ‘I think it was about half an hour a week at first, it wasn’t much, but it started the ball rolling in developing a coping strategy,’ said Heather.

Thomas had no concentration, couldn’t sit and play a game, and was extremely agile. Therapists advised on toys and games such as large alphabet bricks and coloured balls, and showed how to train him to sit and engage in play, such as “catch”.

‘It was very structured play, fun for him, and he would get rewards he liked, like bubbles,’ said Heather. As a result, by the age of five he was beginning to use single words.

Today, Thomas, who falls in the middle of the autistic spectrum, is still only partially verbal. ‘He will never be able to speak fluently,’ said Heather.

Until secondary school, he went to an ordinary local primary school, which had a department for children with autism. But because there were no learning facilities for autistic children at secondary level locally, his parents decided a residential school was the only option.

There wasn’t much choice, but they spent a year looking for the right one for Thomas, which Heather regards as ‘a journey’ in which they had time to come to terms with him leaving home.

It wasn’t easy for the family then, and isn’t now. Visits are often brief, despite the long journey for Heather and her husband.

‘He’s happy and pleased to see us but there isn’t a lot we can do together, or to talk about. He’ll have lunch with us then want to go back to school, and he’s not bothered when we leave,’ she explained.

Thomas’s autism has influenced the whole family’s choices. Heather started doing voluntary work with NAS working with children and families with autism and was eventually offered a job. Her other two children also now work in the autism field, though her son was embarrassed at having an autistic brother when he was teenager; he and his sister both think the world of him now, and say they are better people because of him.

What worries Heather and her husband is what will happen to Thomas when he’s 19 and will have to leave school.

‘He could be back at home, but looking after him would be a full-time 24/7 job. He always has to have someone with him, he has no sense of danger and is very vulnerable,’ says Heather.

Thomas can wash and dress himself with supervision, but couldn’t leave the house on his own, and certainly wouldn’t be able to shop – even though he knows what coins are worth he can’t count them.

‘It’s very scary,’ said Heather. But Thomas is unaware of how his future will change. ‘He just lives day-to-day.’

And for the moment, Heather and her husband are taking one day at a time too while they explore the range of options for Thomas’s care and choose the best one for him.

Sue Hahn, Deputy General Manager at Milton Park Hospital, Bedfordshire, a specialist hospital for people with Asperger Syndrome, has a daughter with autism, and the family has undergone many similar experiences to the Wildsmiths.

Visiting her daughter at her residential placement can be painful. Sometimes visits are only half an hour.

‘She couldn’t sustain a whole day. She’d be pleased to see me and we’d have hugs, but there’s no shared pleasure. It can be very lonely for parents,’ she says.

CHANGING SERVICES

In September 2011 the National Institute for Health and Clinical Guidance (NICE) published guidance for health professionals on ‘improving the recognition, referral and diagnosis of children and young people with autism’. Its aim is to speed things up to get quicker and better support for families.

Next year, in November 2013, NICE is due to publish another set of guidance, this time on ‘the management of autism in children and young people’.

The window on autism awareness is getting flung wide open at last.

