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Children with autism can display a bewildering range of strange behaviours and obsessions

The autism myth

Everyone knows this disturbing disorder is reaching epidemic proportions. But all may not be what it seems, says **Graham Lawton**

RICHARD Miles will never forget the winter of 1989. The 34-year-old company director and his family spent that Christmas on the island of Jersey in the English Channel, where he had grown up. It was also then that he first noticed something was badly wrong with his 14-month-old son Robert. The bright, sociable child, who had already started talking, became drowsy and unsteady on his feet. Then he started bumping into furniture. Within weeks his language had dried up and he would no longer make eye contact. "It was as if the lights went out," says Miles. His son was eventually diagnosed with autism.

Miles, who now campaigns for more research into autism, is convinced that his son is part of an autism epidemic. Ten years ago, he points out, Jersey had just three autistic children in special-needs education. It now has 69. Robert was one of a cluster of nine children on the island diagnosed around the same time.

Similar rises have been reported across the world, from Australia to the US, and from Denmark to China. Back in the 1970s, specialists would typically see four or five cases of autism in a population of 10,000. Today they routinely find 40, 50 or even 60 cases. Perhaps the starkest illustration of autism's relentless rise comes from California. In 2003, the state authorities stunned the world when they announced that over the previous 16 years, the number of people receiving health or education services for autism had risen more than sixfold. The world's media went into overdrive.

What could be causing so many children to lose their footing on a normal developmental trajectory and crash-land into the nightmare world of autism? The change has occurred too suddenly to be genetic in origin, which points to some environmental factor. But what? There is no shortage of suspects. In the UK, blame is often laid at the door of the combined measles, mumps and rubella (MMR) vaccine. In the US, mercury added to a range of childhood shots has been accused. Food allergies, viral infections, antibiotics and other prescription drugs have all been fingered, often by campaign groups run by mystified and angry parents. The problem is that none of these suggested causes has any solid scientific evidence to support it (see "The usual suspects", p 40).

Perhaps there's a simple explanation for this: there is no autism epidemic. On the face of it that sounds ridiculous – just look at the figures. But talk to almost any autism researcher and they will point to other explanations for the rise in numbers. Some say it's still an open question, but others are adamant that the autism epidemic is a complete myth. And if the most recent research is anything to go by, they could be right. Studies designed to track the supposedly increasing prevalence of autism are coming to the conclusion that, in actual fact, there is no increase at all. "There is no epidemic,"

As diagnoses of autism in California have soared, the state has increased treatment services



says Brent Taylor, professor of community child health at University College London.

Autism is a developmental disorder sometimes noticeable from a few months of age but not usually diagnosed until a child is 3 or 4 years old. It is characterised by communication problems, difficulty in socialising and a lack of imagination (see "What is autism", p 39). It is not a single disorder, but comes in many forms, which merge into other disorders and eventually into "normality". There is no biochemical or genetic test, so diagnosis has to be made by observing behaviour. Autistic children also often have other medical conditions, such as hyperactivity, Tourette's syndrome, anxiety and depression. The upshot is that "one person's autism is not another person's autism," says epidemiologist Jim Gurney of the University of Minnesota in Minneapolis.

In recognition of this ambiguity, autism is considered part of a continuum within a broader class of so-called "pervasive developmental disorders" (PDDs) – basically any serious abnormality in a child's development. Autism itself is divided into three categories: autistic disorder, Asperger's syndrome (sometimes called "high-functioning autism"), and pervasive developmental disorder-not otherwise specified (PDD-NOS), sometimes called mild or atypical autism. Together these three make up the autistic spectrum disorders.

Confused? You're not the only one. The difficulty of placing children with developmental problems on this spectrum has led to several major shifts in the way

"Californian authorities stunned the world when they announced a sixfold rise in autism over the past 16 years"



SUSANNA FROMM/NEWS.COM

People with Asperger's syndrome, like 7-year-old Brandon Mendel of Sunnyvale, California, can have difficulty empathising with others

autism is diagnosed in the past 30 years. In the late 1970s, the autism label was kept for those with severe problems such as “gross language deficits” and “pervasive lack of responsiveness”. But since 1980 the diagnostic criteria have been revised five times, including the addition of PDD-NOS in 1987 and Asperger’s in 1994.

This massive broadening of the definition of autism, particularly at the milder end of the spectrum, is one of the main factors responsible for the rise in cases, says Eric Fombonne of McGill University in Montreal, Canada, a long-standing sceptic of the epidemic hypothesis. Tellingly, around three-quarters of all diagnoses of autism today are for Asperger’s and PDD-NOS, both of which are much less severe than the autism of old. “There is no litmus test for who is autistic and who is not,” says Tony Charman of the Institute of Child Health at University College London.

Changes in diagnostic criteria apart, there are other reasons to believe that autism is simply being diagnosed more often now than in the past. One is the “Rain Man effect” – the huge increase in the public awareness of autism following the 1988 film starring Dustin Hoffman. Awareness has also increased massively among healthcare workers. “Twenty years ago there were maybe 10 autism specialists in the country. Now there are over 2000,” says Taylor.

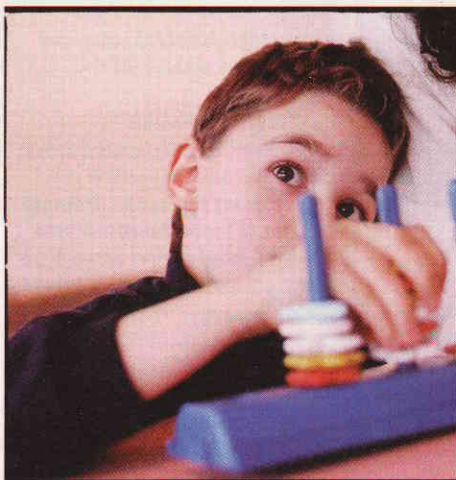
Another factor is that one of the stigmas of autism has largely disappeared. Until about 10 years ago a prominent idea was that autism was caused by an unloving “refrigerator mother”. Now it is a no-blame disease. “Parents are more willing to accept the label,” says Taylor. One expert *New Scientist* spoke to went as far as to describe autism as “trendy”.

Finally, while some parents still have to fight for help for their autistic children, far more services are now available. This has encouraged doctors to label borderline or ambiguous cases as autism – they know this is often the best way to get the child some help. It also makes autism an attractive diagnosis for parents.

“I hear stories of parents who are anxious to get a particular diagnosis if that is what is required to obtain the services their child needs,” says Sydney Pettygrove, a paediatrician at the Arizona Health Sciences Center in Tucson. In the UK, says Simon Baron-Cohen of the Autism Research Centre at the University of Cambridge, “in every town there are trained clinicians who can make a diagnosis.”

It is hard to quantify these trends, but many epidemiologists now believe that they can account for the apparent rise in autism the general public and media take for granted. Proving it, however, is difficult – if not impossible. The main problem is that an epidemiological study carried out in the 1980s simply cannot be compared with one done last week. There will be so many differences in diagnostic procedures and in the willingness

Children with autism can be helped by intensive therapy, such as that given in this centre in Saint-Dies-Des-Vosges, France



DUNG NGUYEN/GETTY IMAGES

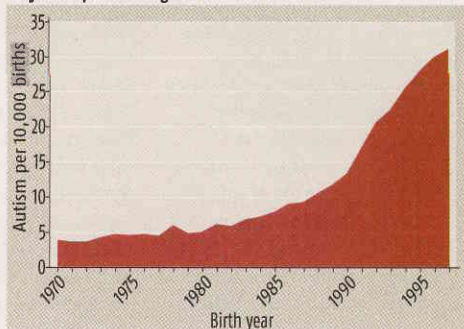
of doctors and parents to label a child autistic that comparisons are meaningless. “You can’t control for everything,” says Charman.

And so attention has shifted to what epidemiologists sniffily refer to as “service provider data”, such as the California figures. Ever since 1973, the authorities there have been keeping records of the number of people receiving some kind of state help in connection with autism. In 2003, California’s Department of Developmental Services (DDS) announced a chilling figure that captured the world’s attention. In the 16 years to 2002, cases rose from 2778 to 20,377 (see Graph, above). Among autism campaigners these figures are often cited as incontrovertible and final

“Prisons and institutions could be full of autistic adults labouring under wrong diagnoses such as schizophrenia”

EPIDEMIC OR ILLUSION?

In California, the autism rate among people born in 1997 is much higher than among those born in 1970. This has been taken as evidence of an autism epidemic, but experts say there are other ways to explain the figures



SOURCE: CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

proof of the existence of the autism epidemic.

But there are serious problems with this interpretation. First, the figures are raw numbers from public services, not a proper epidemiological study. Critics point out they are not corrected for changes in diagnostic criteria or for the growing awareness of autism.

There is evidence, for example, that as the California autism numbers have risen, diagnoses of mental retardation have fallen. Researchers at Boston University School of Medicine in Massachusetts have found a similar pattern in the UK. This effect, dubbed “diagnostic substitution”, cannot explain all the increase but is one example of how diagnostic fashions can skew the data.

What is autism?

The developmental disorder that is now called autism was first described by doctors in 1943. Psychiatrists say there are three key features: lack of imagination, communication difficulties, and problems interacting with others. In practice, those affected have a bewildering range of strange behaviours. These can include fear of physical contact, hearing and visual problems, bizarre obsessions and a touching inability to lie.

Apart from the fact that about three-quarters of those affected are male, it is hard to make generalisations because the

condition varies widely between patients. Contrary to popular belief, freakish talents for maths or music, say, are uncommon. In fact, about three-quarters of people with autism have learning difficulties, but those who do not may manage to hold down a job.

Parents usually realise something is wrong because children fail to develop normally. But up to one third of cases are “regressive” – children seem to go backwards when they are about two, losing their language and social skills.

In psychological terms, people

with autism seem to lack “theory of mind” – the recognition that other individuals may hold a different perspective on things than themselves. This leaves them in a bewildering world where people seem to act according to incomprehensible rules and behave in meaningless ways. They also have impaired “executive function”, the ability to plan future actions. And patients have weak “central coherence”, the ability to extract meaning from experiences without getting bogged down in details. In other words, they can’t see the wood for the trees. Clare Wilson