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Katie Grant - Autism: we need a debate

Her column last week prompted a vociferous reaction, reflected in the column and letters, at the bottom of this web page. Here Grant answers the critics.

My views on autism last week upset many people who have autistic children. I am sorry for the pain, but not for raising the issue. My desire was — and still is — to question the reliability of the most recent statistical analysis of autism in Scotland. I believe work needs to be done to differentiate between those who have the condition and those who do not. Unfortunately, this past week I have become something of a hate figure for those who are not even prepared to concede that this matter should be debated.

I would ask those who have written attacking me to consider these words: “There is a risk of the diagnosis of autism being extended to include anyone whose odd and troublesome personality does not readily fit some other category. Such over-inclusion is likely to devalue the diagnosis to a meaningless label.” This was written by Dr Tom Berney in the British Journal of Psychiatry. He is a lead clinician and autism specialist at Northgate and Prudhoe NHS Trust in Morpeth. He was writing in 2000, when figures were far lower than they are today.

There are others within the health profession who privately share Berney’s view, perhaps reluctant to confront the wrath of a lobby group that has called into question my motives in writing the article. The fact remains that the question of autism diagnosis needs far more debate and examination. Suggestions from individuals and groups that my column should not have been published — and that the views contained should not have been expressed — are downright dangerous, not just in the context of freedom of speech, but also to those people struggling to cope with genuine cases of autism.

I support wholeheartedly all those whose children need to be helped, but autism should not be hijacked and turned into a woolly generic term. It should retain its diagnostic integrity. The condition exists and as a society we need to deal with it. But, faced with a massive statistical increase in autism, we have a duty to examine all the causes of children’s behavioural difficulties. If sceptics about official statistics are shouted down, there can be no debate.

Not everybody who disagrees with my views would have me silenced. Sophie Dow, the formidable founder of Mindroom, the charity dealing with learning difficulties, agrees a wider debate would be most welcome. Dow is against any of the different camps in this debate claiming exclusive understanding. “We need to accommodate all theories,” she says. “It is very dangerous for one group of people to claim the right to understand what learning difficulties really are.”

For a condition only identified in 1943 and only distinguished from schizophrenia in 1971, autism clearly is an evolving concept. As there is no cure, ideas and theories play a large part in both diagnosis and treatment and, as many experts, including Berney, agree, diagnosis is extremely difficult.

We need to find out more about why children develop what Berney described as “odd and troublesome personalities”, and any research must include not just the personal but also upbringing, family circumstances and other societal factors.

“Over-inclusion” — making autism a catch-all for various complaints — cannot help those children or their families whose plight is genuine. As Berney says, putting somebody on the autistic spectrum cannot become the default option, since once a label becomes meaningless, help is far less likely to be forthcoming. When figures for those on the autistic spectrum rise dramatically we must be as certain as we can be that each diagnosis not only is completely legitimate, but is recognised as such so that when help is needed, we all listen attentively.

Half a million people in Britain fall within the autistic spectrum, although it must be remembered that this figure increased when people with Asperger’s syndrome, who are often extremely clever and manage to integrate reasonably well, were included.

Last May’s BBC Horizon focussed on the controversy surrounding the triple vaccine MMR and its supposed link with autism. It found “rising awareness of autism has undoubtedly played a role in the increasing numbers,” particularly as there is “no objective test for autism and therefore the numbers diagnosed depends on the skill and experience of the medical community”.

These skills, as most would agree, have ‘improved significantly’ but when the goal posts keep changing, violent alterations in statistics are bound to follow on.

A study by Drs Jick and Kay at Boston University Medical School revealed that “as more people have been diagnosed with autism, there has been a similar decrease in other less specific diagnoses (such as ‘behaviour’ and ‘developmental’ disorders)”. Though you may disagree — and many do — that bad behaviour, as opposed to a behavioural disorder, is sometimes responsible for increases in autism diagnoses, it at least seems right to ask whether autism, by taking in other previously individualised disorders, is becoming too much of a “catch-all”.

It often seems that the MMR controversy, which still rumbles on, has hijacked any other debate about the autistic spectrum. Yet nobody has more of an interest in getting the diagnosis right, and removing from any list those who should not be on it, than those faced with autism every day.

“There is a need to define clearly what the correct numbers are to provide the appropriate statistics and then the appropriate help,” says Professor Lawrence Weaver, a consultant paediatrician at the Royal Hospital for Sick Children at Yorkhill, particularly as, so he points out, “the more you look for something, the more you find it”.

The numbers of children on the autism spectrum that he sees are growing and, by the time they reach Weaver, there is no doubt about their condition. Nevertheless, he thinks statistics must always be treated with caution, particularly statistics over diagnoses which cannot, by their nature, be completely objective. “Physicians must constantly ask themselves two questions: one about definition and one about ascertainment,” he says.

Since being on the autistic spectrum is not like having chicken-pox — there are few fail-safe physical signs like a rash, for example, and no two autistic children, just like no children, are exactly the same — great care must be taken.

We live in confusing times where mental health is concerned, and even the experts have a huge amount to learn about autism and its symptoms. Definitions of autism are not set in stone, and nor should they be. Yet this has its dangers. Berney concludes that autism can, at times, be “indistinguishable from a dissocial personality disorder”.

Those who live with autism can only be helped by opening up the debate. Shouting down those with unpopular views will do them no favours at all.

It's not a trendy excuse

Children with a disability should not be treated as a source of ridicule, but time and again they are. For every article that is sensitively written about the difficulties families dealing with disability have to face, there are countless others — like Katie Grant’s column last week — that decried the rise in diagnoses as an “epidemic” and an excuse for children to be “badly behaved”.

What would you think if you read that nine out of 10 cases of autism were just a fashionable excuse for bad behaviour? This type of reporting is why parents move their offspring away from the “naughty” child as if they were contagious, when the child in question is simply unable to understand human interaction. Except this isn’t naughtiness we’re talking about. Autism is a lifelong disability that permanently changes families’ lives.

If I had £1 for every time someone said to me, “It’s just a stage he’s going through,” or strangers demanding, “Why can’t you control your son?” then I’d be able to retire to somewhere hot to live the “fashionable” lifestyle Grant described last week.

Grant gives the impression that the diagnosis of autism is a gravy-train to Prada whereas, in reality, parents with autistic children are battle-scarred veterans. The fight for diagnosis is just the beginning. Assuming you don’t get accused of Munchausen’s syndrome by proxy (MSBP), and can find a specialist who takes you seriously.

The disability living allowance (DLA) forms are heartbreaking. Being forced to describe just how different your child is from the norm shakes most people to the very core. Grant assumes that people can stroll in and demand DLA; it’s not true. In our support group, most parents were turned down; the vast majority only received middle or lower band after appeal. That’s worth as little as £16.50 a week.

Grant exhorts us to seek the “true reasons they (children) are doing badly at school”. This can be answered simply. With the political pressure on special schools, children have been forced into the mainstream, often with disastrous results. Teachers are ill-equipped to cope due to inadequate resources.

No parent would want a diagnosis of autism. No parent chooses to be shunned by some family and friends. No parent wants to be criticised almost every time they leave the house.

When I see my eight-year-old daughter and three-year-old son caring for their brother, I feel fiercely proud of all three. Autism isn’t about bad parenting; it’s about fantastic children.

Michaela Child is founder of ASDfriendly, an internet-based support network for parents

Increase is no surprise

KATIE GRANT’S article suggests that the increase in the number of young people diagnosed should be treated with caution. This is a reasonable point. We should note, however, that our understanding of autism has moved on over the past 10 years. We are now more informed and better able to identify autism. Similarly, there are improved systems for diagnosis, with a rise in diagnostic resources throughout the country, although long waiting lists across Scotland still prevail.

In many subject areas, improved understanding and reporting leads to increased identification of problems that have been there previously, but not dealt with appropriately. This is also the case in other social concerns such as domestic abuse. We should, therefore, not be surprised by the increased diagnosis of more young people with ASD if the system is working more efficiently.

The article suggests that there may be a queue of people aspiring to achieve the “fashionable” label of autism. This assertion is particularly unhelpful. I do not know any individuals with autism or families who have sought out a diagnosis as a trendy accessory for their lives. To suggest this is simply uninformed.

The article may well have been offensive to thousands of individuals with autism and for many parents whose children live with the disorder. The reality for many individuals and families involves considerable stress, fear and anxiety.

John McDonald, Chief Executive, the Scottish Society for Autism

SENSATIONALISM: Katie Grant's article in last week's Sunday Times left many people in Scotland shocked. Autism is not a consequence of poor parenting. That autistic spectrum disorders are still under-diagnosed is a given fact; that diagnostic criteria have widened over time is common knowledge.

What possible evidence does Grant have for her claim that "the condition has been adopted by many other parents on behalf of children who are not ill, just badly behaved"? When autism was first identified as a condition in the 1940s, a theory developed that parents were to blame. Such psychogenic theories were discredited 50 years ago, so it is sad to see them even hinted at again.

Worse still, we are asked to believe parents would seek this particular "ism" — the "ism" that dominates Grant's article is nothing short of sensationalism.

Professor Aline-Wendy Dunlop, National Centre for Autism Studies, University of Strathclyde

APPALLING BEHAVIOUR: Full diagnosis of an ASD can take from 18 months to two years, with input from parents and health, social and education professionals. To accuse these people of diagnosing a child with ASD for petty behavioural issues is appalling.

Does Katie Grant believe parents would place their child under the supervision of an educational psychologist, social worker and speech therapist, be given a record of needs and placed in a special unit, in order to receive an extra £80 a week, or a free taxi to school?

Stephen Carr, Falkirk

CHEMICAL OVERLOAD: Ms Grant should consult with toxicologists, biochemists and environmental researchers about the various chemicals inundating children, which affect their behaviour, abilities and health.

For my autistic son, repeated exposures to mercury pushed him to a toxic tipping point. However, with testing and treatment he improved drastically. People such as Grant and our unresponsive governments discourage proper testing and treatment for these sad, poisoned children.

Nancy Hokkanen, Minneapolis, Minnesota, USA

NO RICH PICKINGS: I've been submerged in autism for five years now, day and night, with precious little financial assistance towards a condition that has already cost our family £35,000. Where are these parents who view autism as trendy and who find the "rich pickings" of benefits so irresistible? I've never come across one.

Stephanie Grabiec, Nottingham

LACK OF RESEARCH: Katie Grant is confusing autism with ASD when she suggests there could be any level of confusion between a neurotypical child with bad behaviour and a child suffering from ASD. When a child has autism there is no doubt whatsoever about their inability to behave normally. She obviously put very little research into the article.

Rebecca Hoskins, Alnwick, Northumberland

THAT'S LIFE: The 600% increase in autism is quite simply due to the fact that medical professionals (and other individuals) are becoming more aware of the condition. A lot of research has already been carried out, but more still needs to be done.

It would have been far better to have raised awareness of the condition by doing a feature on how this disability can affect people. A child in a wheelchair is given much more sympathy than a child with a mental health disorder. Unfortunately, that's life, but articles like the one published don't help.

Caroline Muir, Edinburgh