



**Des Spence**  
on how modern  
medicine  
stopped  
caring, p 388

## VIEWS & REVIEWS

# Professional duty meant I couldn't fight rumours

PERSONAL VIEW **Gillian Needham**

I was facilitating on a residential course when I opened the email that starts this story. It was from a colleague and contained material from a post on an open forum of a professional website. The words were shocking, my colleague was concerned, and there was an indication that the poster was a doctor in training on my patch. The post contained violent intent and foul language directed against a high profile medical colleague. It was material that was difficult to overlook because the views expressed and the language used would surely alarm the public. The doctor's likely name was evident from the post. It seemed correct, instinctively—and with hindsight it still seems correct—to forward the email to one of my team for further exploration. I would be out of the office for a while, and this extract was sufficiently disturbing that the writer surely needed help. It didn't take long to find that the poster was indeed in one of our programmes, and this doctor acknowledged authorship.

Here started a dichotomy of actions, by the employer to protect patients and by the deanery with a duty of care to the doctor. And as a farewell to the internet forum the doctor in question announced suspension from work. This post created spiralling interest online that spilled out of the professional website that was

hosting the forum and into the wider media. Whistleblower sites rapidly picked up and were leading on the story, and a process of personal attack was mounted on several fronts. I received calls from journalists about the story, and it was parodied in blogs and the press and was the subject of critical material on the radio and in a biweekly satirical publication. And that's just what I knew about, without trying to find all coverage. Indeed *BMJ* readers might be surprised—and the wider public perhaps more so—to see some of the material that circulates on blog sites that members of our profession use.

My family was implicated. Beware if your children live with you and are on the electoral roll, as they may by implication be viewed as potential love interest by critics—I “live with two men.” And then I was reported to the General Medical Council with concern for my fitness to practise. It was 15 months before the case was concluded, “with no further action.” Letters were sent to the Scottish health secretary and chief medical officer seeking action against me—signed by colleagues in the NHS.

I felt at the centre of a media storm that purported to be claiming the high ground of freedom of speech, a human right I too cherish, but with no ability to exercise the right myself. And with no such right extended to my family.

Those colleagues who publicly supported the doctor's right to freedom of speech were not deterred by ignorance of the original offensive material (which had been rapidly removed, along with other similar foul posts from the same source) and seemed to recognise no link between freedom of speech and professional responsibility.

I also had a duty of care to the assumed victim of the story, who had been suspended by the employer while due process around clinical governance was pursued. In medical education we take this duty of care to our trainees seriously. It is a journey that we share with our doctors in training. Just as with our patients, records are kept from medical “birth” (entry to medical school) to medical “death” (retirement from practice) to support those who need it and of course to ensure that another freedom is exerted: freedom of individuals to gain access to information about them, while protecting such data from unnecessary intrusions.

Telling my story ran the risk of exposing one of my trainees, and that would clearly have been a breach of my duty of care—so I said nothing in my own defence. I didn't correct the factual inaccuracies that with repeated telling became the assumed truth. Had the content of the blogs been made public, it is likely that their authors would have received no sympathy from the press or public. You could argue that patients also have a right to know when doctors' behaviour puts their professionalism in question. My experience only underlined my inclination to avoid such seductive communications in future. Even now I doubt that more than a handful of people really know what happened here, or why, from each player's perspective. But I did the right thing: I'm sure of that, and that's all that matters to me. But search me on the internet and you'd never know—and nor will the public.

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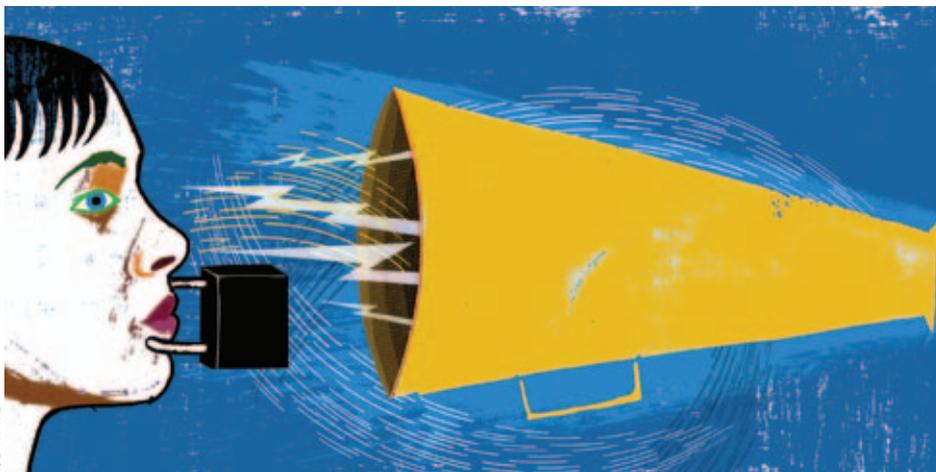
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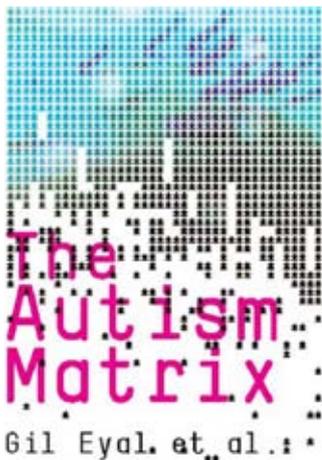


ROB WHITE

REVIEW OF THE WEEK

# How the autism epidemic came to be

The marked rise in autism may be the result of changes in diagnostic criteria. But what led to developmental disorders in children being reconceptualised? **Iain McClure** enjoyed this book that tells the story from a sociological perspective



**The Autism Matrix**

A book by Gil Eyal, Brendan Hart, Emine Oncular, Neta Oren, and Natasha Rossi

Polity Books; £17.99; pp 240

ISBN 978-0745644004

Rating: ★★☆☆

The word “autism” and its adjective, “autistic,” have become high profile terms in the 21st century, and we show no signs of becoming less interested in them and what they mean. The most recent books or articles about autism have been written by clinicians, parents, or “higher functioning” autistic people themselves. Now Gil Eyal and colleagues, five sociologists from Columbia University, have brought a fresh perspective from a different discipline to try to explain autism’s expansion in prevalence and popularity.

Focusing mainly on the story as it has developed in the United States, the authors describe a collision of disparate events that have caused what seems to be a current epidemic of autism. Conventionally, the undoubted rise in its prevalence in recent years has been explained by such factors as changed diagnostic approaches and a widening of diagnostic criteria. The authors do not dispute this, but they seek

to examine the underlying forces that explain why these and related changes have happened.

The authors assert that part of the explanation is a process of “diagnostic substitution.” After the end of the second world war increasing numbers of children and young people began first to be denied admission to institutions for mentally impaired people and then actively discharged from them. Patients who might have languished in the back wards of such hospitals were being rehabilitated into the community by the 1960s and 1970s. Increasingly they were found not to fit existing diagnostic criteria for “mental retardation” or the (even more offensive to modern ears) rapidly dwindling categories of “moron,” “imbecile,” and “idiot.” They were, it was gradually realised, people who either had autism or who were “autistic-like.” The authors cite compelling statistics from the past few decades that show, with a corresponding reduction in the prevalence of mental retardation, the recorded number of autism cases beginning to increase.

But this is only part of the story. In the postwar period and into the 1960s a different disorder, childhood schizophrenia, was also rapidly increasing in prevalence. US child psychiatrists such as Loretta Bender attained high national profiles by diagnosing this condition in many children, and a process began

whereby the diagnostic concept was stretched to cover an ever wider range of cognitive, emotional, and behavioural states. By the 1970s, however, parents and some clinicians (especially non-psychiatrists) began to lose confidence in this illness concept. The treatments offered by Dr Bender and her like-minded colleagues, ranging from psychotherapy to electroconvulsive therapy, often weren’t working. But other approaches, such as “operant conditioning,” borrowed from small scale research with mentally retarded people, were. Parents, dissatisfied with the idea of their children being labelled by psychiatrists as either ill or untreatable and retarded, wanted to find a new way to understand their children. The authors argue that what resulted from these almost tectonic shifts in the conceptualisation of mental disorder in children was that, from the 1970s, an interstitial territory opened up between the illness concept of childhood schizophrenia and the congenital damage of mental retardation.

In its final third the book goes on to explain how autism began to fill this interstitial zone to become what is now “the prototypical form of developmental disability.” I learnt new information about the small number of charismatic individuals, such as Ivar Lovaas, Bernard Rimland, and Lorna Wing, who have

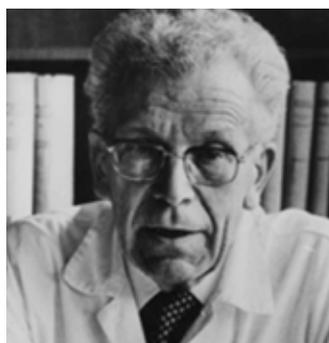
been key players in this autism story. They forged a parent based movement that ignored conventional theories about the causes of autism and intervention (expounded mainly by psychiatrists). Crucially, they harnessed this parent power to support research into therapies and promulgate consequent behavioural based interventions that actually delivered meaningful change for patients and their families.

Overall I found much to admire in this detailed study. Perseverance bore particular fruit when the authors explored the work of Leo Kanner and Hans Asperger in 1943-4. I knew that these two doctors, one a psychiatrist and one a paediatrician, had at that time independently reformed Eugen Bleuler’s schizophrenia symptom of “autism,” but I didn’t know why. Eyal and colleagues explain that the men occupied—almost personified—the interstitial territory outlined in this book’s earlier exploration. Kanner and Asperger didn’t discover autism; they simply described it in a different way than anyone had before, because of their shared German psychiatric education. This tradition enabled them, as relative non-conformists in their respective disciplines, to conceive a new way that a person could exist. Independently but not coincidentally, the authors explain, they coined the phrase “autistic.” A totally different form of human existence had henceforth been conceived, and autism cascaded through the 20th century, gathering strength and numbers exponentially. What will happen next?

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**Asperger (left) and Kanner independently reformed the symptom of “autism”**

BETWEEN THE LINES Theodore Dalrymple

## Full of bile

No writer can have expended more bile on his homeland than Thomas Bernhard (1931-89). Not only were his books and plays extremely insulting to his country, Austria, but in his will he directed that none of his books should be published there (“whatever form the state takes”) and none of his plays should be produced on its stages. Of course, such obsessive rancour is not always easy to distinguish from love, albeit disappointed love.

Bernhard was infuriated by the distinction between the great natural beauty of Austria and of its human monuments and cultural achievements, on the one hand, and its moral obtuseness and will to amnesia after the war, on the other.

But there was another possible source of his misanthropy in general and his Austrophobia in particular: his illness. All his life he struggled for breath, and eventually he died of pulmonary sarcoidosis. He spent much of his early adulthood in hospital, he could never take the simple act of breathing for granted, and he often alluded to the fear of death as the motive not only for his creativity but for all creativity. Chronic illness calls forth heroic fortitude in some, but it exasperates or embitters others.

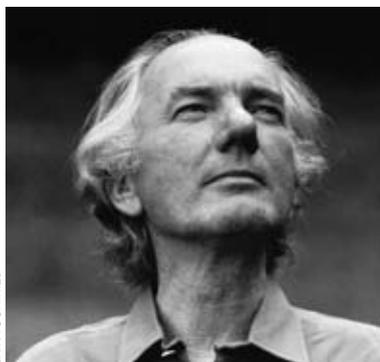
His last book, *My Prizes*, published 20 years after his death, consists of reflections on, and the memories evoked by, the many literary prizes that he was offered in the German speaking world during his lifetime.

In general he pours forth his bile on those who awarded him the prizes and especially on those who attended the ceremonies at which they were presented.

We meet ministers of culture who snore on the platform (and are famous for doing so) and ministers of culture who, until recently, were commissioners of agriculture. Bernhard views the whole process of giving literary prizes as a vulgar and hypocritical sham and accepts them only for the money.

The esteem in which he holds the medical profession does not seem to be much higher than that in which he holds ministers of culture. He tells us

**He tells us that he accepted the prize only because he needed to pay the fees of the supposedly outstanding hospital for pulmonary diseases**



ERIKA SCHMIED

**Thomas Bernhard: sick of Austria**

that he accepted the prize of the cultural circle of the Federation of German Industry in 1967 only because he needed to pay the fees of the supposedly outstanding hospital for pulmonary diseases (“still attached to the Steinhof lunatic asylum”). “I was in the Hermann pavilion, where there were seven rooms with two or three patients each, all of whom died during my stay, except for a theology student and me.”

He had been given up for mortally ill with cancer by his doctors, but a Professor Salzer took a biopsy and diagnosed an incurable but not immediately fatal “Morbus Boeck” (sarcoidosis). Bernhard did not think much of the professor, before whom everyone grovelled: “Even if he couldn’t perform miracles and could only, with the best of intentions and with extreme skill, cut and mutilate living patients, I used to see him every week in

the process of sending, according to a carefully elaborated plan, the victims of his noble science to the grave, much more quickly than if he had let nature take its course.”

Bernhard did not mince his words. He resigned from the Darmstadt Academy of Language and Literature on the occasion of the election to it of the former president of the federal republic, Walter Scheel. Bernhard pointed out that he often received black edged notices of the deaths of the academy’s members, but he soon hoped to receive such a notice of the death of the academy itself. He didn’t please everyone.

Theodore Dalrymple is a writer and retired doctor  
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## MEDICAL CLASSICS

### Doctors

A television soap opera on BBC One, first screened in 2000

As I sat in the restaurant with the then producer of the BBC One drama series *Doctors*, his eyes glazed over. We were meeting to see if I’d be interested in becoming a medical adviser to this brand new programme, and he’d asked me about the common health problems we see in general practice.

Enthusiastically I told him about coughs and colds, sore ears, muscle aches and pains, and athlete’s foot—the bread and butter of life in general practice. Clearly this was not the way to impress or excite. But when I mentioned the rare and unusual possibilities of a pregnant woman’s waters breaking, people collapsing, and haemorrhage, suddenly his eyes lit up. And we had some of these in our very first episode, which was transmitted in March 2000.

*Doctors* is set in a fictional Midlands general practice



that, through the wonders of television, has patients from the inner city and the suburbs and even some who live on working farms. The main practice, the Mill, also has a branch

surgery on the local university campus.

So far 26 doctors have worked at our practices, including police surgeons, a forensic archaeologist, and someone running a private Botox clinic. Obviously they are caring, tireless, good looking, and multitasked—otherwise they wouldn’t be on television—and they always make the diagnosis. But to redress the reality balance some of our doctors have also had alcoholism and addiction to gambling, committed fraud, and had affairs, some more than once.

The programme doesn’t shy away from anything, and to its credit it doesn’t only feature uncommon conditions, even though the principles of television—“rare in real life means common on television” and “if it can happen in real life then it will happen on television”—may be called on to justify some stories. Common conditions that often struggle to get media coverage, such as chronic obstructive pulmonary disease, appear often. I believe that *Doctors* gets the balance right between entertainment and being informative and educational. This is reflected in the favourable responses from the public and the medical profession alike, something that isn’t easy to achieve. Awards have come our way too: we’ve won nine British soap awards and received two BAFTA nominations among others.

Obviously we draw criticism from time to time, the most memorable to me being from an older woman who said that she didn’t enjoy the story involving sperm because she was eating her lunch at the time.

*Doctors*, 2000 episodes in, is on our screens five days a week and is, as a surgeon told me, “perfectly timed between the end of lunch and the start of my afternoon list.”

Rob Hicks, general practitioner and adviser to *Doctors*

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# Care less

FROM THE  
FRONTLINE  
Des Spence



**bmj.com archive**

► Observations:  
Repeat after me: “Mid  
Staffordshire”  
(*BMJ* 2010;340:c188)  
► News: Full public  
inquiry gets under way  
(*BMJ* 2010;341:c3952)

We all care—about the environment, the developing world, and poor people. We express our commitment by spending thousands of pounds to send our children to dig toilets in Africa for two weeks, by buying organic chicken, by sharing the school run.

So, do doctors care? This seems an impertinent, almost ridiculous, question. In every medical school interview teary candidates bleed out their care and commitment to humanity: “I just want to help.” Actually, does it matter whether doctors care? The job is increasingly a function of diagnostics. We have moved beyond futile handholding “care” to tangible treatments. Indeed vocational caring is an outdated concept. Improved organisation, shift work, technology, and multidisciplinary and multiagency integrated working have greatly improved care. Haven’t they? Professionalism is now defined by academic qualifications; surely there is no need to demonstrate vocation. We are but overpaid technocrats; simply caring isn’t relevant to modern healthcare any more.

However, listening to the testimony of patients from the Stafford Hospital inquiry I do wonder. We know that things go wrong in medicine, events that haunt us in our dreams. But the reported failings in Stafford seem to go beyond this—the hospital was broken. The usual excuses and recommendations are trotted out, and talk is of structural and cultural problems and dysfunctional communication. Everyone was

involved, but no one was responsible, just the usual modern multidisciplinary medical mayhem. A new quango of appointed worthies may be formed to provide more scrutiny and oversight. But the testimony showed that the problem at Stafford was obvious: a lack of care. Were there opportunities for professionals to speak out? Why didn’t professionals speak out? Has personal professional responsibility been snuffed out? Are we now existing in a deprofessionalised comfort zone? And Stafford Hospital is no rogue medical institute: the problems of a lack of care exist throughout the country.

Medicine is blind to the importance of caring, intent on selecting the academic “best” (some medical schools don’t even bother interviewing). But being the “best” is skewed by privilege, and the demographic of medicine is a Cambridge college in terms of diversity. We don’t select on the basis of those who care. So the endless reorganisations of the NHS and delusional initiatives with grandiose titles are doomed to fail. Quality medicine is delivered by professionals who truly care. Doctors must put patients before themselves. Doctors must resolutely hold onto professional ideals, however utterly inconvenient and unbalancing to their lives. It is simply not enough to say we care.

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# We need more rationality around cancer

STARTING OUT  
Kinesh Patel



“I can’t see why I’ve waited so long,” she said. “I’m a cancer patient.”

She had been seen sooner than most. I flicked through the notes to try to get a handle on what was going on. I quickly scanned the last letter from the oncologist, finding it in among a pile of paperwork relating to swabs for *Staphylococcus aureus*, property receipts, and other rather unhelpful documents.

“But you’ve been cured,” I said. “That’s what your oncologist says.”

“Doesn’t matter,” she retorted. “I’ve had cancer.”

Now don’t get me wrong. Cancer causes a great deal of distress and suffering to patients and their families. And the nation considers the big C as that which should be dreaded beyond all else.

But does this justify the huge amount of attention and resources it attracts, more than for all other conditions, many of which are

just as serious? Clinics are full of “two week wait” patients whose symptoms indicate that they may have cancer. The problem is that these symptoms are often so generic that nearly everyone could be referred to hospital as someone with suspected cancer.

The BBC website lists the first symptoms of ovarian cancer as bloating and abdominal pain ([www.bbc.co.uk/health/physical\\_health/conditions/in\\_depth/cancer/ovarian\\_cancer.shtml](http://www.bbc.co.uk/health/physical_health/conditions/in_depth/cancer/ovarian_cancer.shtml)): welcome to any general gastroenterology clinic. As one consultant sarcastically put it, “Anyone who breaks wind a couple of times gets referred up as suspected cancer.”

You could argue that all patients should be seen within two weeks, of course, and that is certainly a target to strive for. But with resources tightening and services all over the country contracting, this is unlikely to be attained in the near future.

The price of all of this is that patients who aren’t thought to have cancer get put at the back of the queue as a result of the prescriptive appointments booking system. It doesn’t really matter what’s wrong with them—from pyoderma gangrenosum to heart failure and everything in between.

It would be a pipe dream to suggest that changes could be made to the current system of cancer referrals. Any tentative changes would be met with a hue and cry loud enough to end any junior government minister’s career. Perhaps it is time for a carefully conducted trial of clinical prioritisation of patients to see how this affects outcomes. In the new NHS, resources solely devoted to patients’ emotional wellbeing can, sadly, no longer be afforded.

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