

The stark black-and-white photograph shows a large, ungainly young woman with a shaven head, wearing shorts and a T-shirt and sitting cross-legged on the floor. Her face is hidden. 'The young woman in this picture has autism,' reads the text beside it, 'a debilitating developmental disorder that affects communication, socialisation and behaviour.'

The next photo shows the helmet she has to use to stop her damaging her head when she bangs it on the wall, her adult-sized nappies and the picture board she has to use, because she can't speak. 'Sometimes she screams, and nobody knows what she's thinking,' explains the text, 'but she's clearly frustrated about her communication disorder.' More pictures show her lying on the floor staring at blocks of wood or sitting in a chair, unresponsive. 'If she had a voice, we wonder... What is she thinking? What would she say?'

These are pictures designed to trigger pity and maybe a guilty twinge of revulsion; they might even move you to make a donation. But you've been suckered. They form the opening pages of an angry radical website designed to challenge familiar stereotypes. They are a knowing and brutal parody of campaigns to raise money to find a cure for a 'terrible disorder'.

They are part of a grassroots revolution by a new breed of autism activists who identify with other once-marginalised sections of society like black people and homosexuals, engaged in the same sort of struggle to establish basic rights and to outlaw discrimination. The first Autistic Pride Day march took place in America this summer and the organisers declared their intention was to 'promote the concept that those identified as autistic are not suffering from a pathological disease any more than those with dark skin are suffering from a form of skin disease'.

This point about the integrity and validity of the autistic state is also hammered home on www.gettingthetruthout.org. After the initial pitiful images, we see the same woman wearing a different T-shirt. It reads: 'Not being able to speak is not the same as having nothing to say.' She may not be able to speak,

but she is fiercely articulate at the keyboard as she lucidly denounces the way autistic people are belittled in the name of 'helping' them: 'I will not have my life medicalised this way so you can fund the elimination of autistic people from the planet.'

There are more than 500,000 people believed to have some (often undiagnosed) degree of autism in this country, and if the radicals are right we could be treating them in completely the wrong way. If this is the case, there are some major implications for many of our assumptions about education, brain sciences and psychology. Last summer, to pick up some clues about what the autistic pride movement wanted and what it might have to teach us, I went to the strongest manifestation of this new consciousness yet to emerge in the UK.

Called Autscape, it was the first conference in Britain organised by and for people with autism, a process described by the organisers as 'like herding cats'. The media stereotypes I carried with me were three: the once-cuddly toddler now screaming and unreachable, lost to his distraught parents; Dustin Hoffman's incompetent but endearing genius calculator in *Rainman*; and the shamelessly inquisitive, literal-minded adolescent in Mark Haddon's *The Curious Incident of the Dog in the Night-time*.

None of them prepared me for the real world of autism; immediately I was struck by the badges they all wore. In place of the impersonal, minimally revealing badges of 'normal' conferences, these were raw shouts from the heart. There were three options. Red meant: 'Do not approach me. I do not wish to socialise with anyone.' Yellow said: 'Do not approach unless I have already told you that you may approach me while I am wearing a yellow badge.' Green declared: 'I would like to socialise, but I have difficulty in initiating. Please feel free to approach.'

My first response was: what a brilliant idea. Who hasn't wished for something similar at a party or ▶

Ways of seeing: autistic children working together on an interactive whiteboard at the Hollies School in Cardiff

SAY IT LOUD, AUTISTIC AND PROUD

For many, it's a condition which evokes pity and even fear.

But a campaigning group of activists is determined to change the way we view autism by dealing not with its many downsides, but by focusing on its positives.

Jerome Burne reports. Photographs **Andy Hall**

'AUTISM ISN'T SOMETHING A PERSON HAS OR A SHELL YOU'RE TRAPPED IN. IT'S A WAY OF BEING'

◀ social occasion? 'I really don't feel like talking this evening unless you are a Bob Dylan fan/Chelsea supporter.' But, more than that, they immediately challenged one of the most pervasive myths: that autistic people lack a 'theory of mind', that they have no sense that other people have an interior world. While non-autistic people can predict social behaviour by imagining what is going on in other people's minds, so the theory goes, those with autism behave as if other people are machines with no inner world. It's this that makes their social skills so poor. But which shows more awareness of others: 'Mark Tucker: Marketing' or 'Do not approach me'?

Shortly afterwards, an even more firmly rooted assumption took a good hammering. Jim Sinclair is one of several legendary American activists, the founder of Autism Network International, and he has been organising a similar event, Autreat, in the States for nearly a decade. He is diagnosed as autistic and uses a wheelchair, however his clarity and intensity makes him a commanding figure. He tackles the hugely sensitive issue of the emotions of parents whose child has been diagnosed with autism. Few of us 'normals' could do anything else but mutter inarticulate sounds of consolation. But in discussing it, Jim is far clearer – and sterner.

'These parents are grieving, but this grief does not stem from the child's autism,' he pronounces. 'It is a grief over the loss of the normal child the parents had hoped and expected to have. But this grief over a fantasised normal child needs to be separated from the parents' perceptions of the child they do have: the autistic child who needs the support of adult care-takers and who can form very meaningful relationships with those care-takers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both parents and the child.'

It is a point vividly made on www.gettingthe-truthout.org. 'I began to know that my future



Meeting of minds: (above) autistic academic Mike Lessing at home in London; and, top, an activist poster by Ralph Smith



lay in an institution,' writes an anonymous author. 'Or maybe on the streets. Or dead. Because that's what everyone around me believed would happen if I wasn't cured. I reacted to this knowledge the way a lot of people do. I began my reign of terror. Other people's response was to increase the restrictions on my life until I spent most of my time tied down and isolated from not only the outside world but the rest of the institution, too.'

This is not a picture of someone cut off, unable to respond to the words and actions of others – rather she picked up their messages all too clearly. It's the sense of not being valued, not being respected for who you are, that gets to the heart of the radicals' complaint.

'Autism isn't something a person *has* or a "shell" that a person is trapped inside,' says Jim. 'Autism is a way of being. It is pervasive. It colours every experience, every sensation, perception, thought. So when parents say, "I wish my child did not have autism," what they are really saying is: "I wish the autistic child I have did not exist."

Time and again at Autscape, I heard variations on this refrain that autistic people want to be valued, not to be regarded as damaged goods that need to be fixed. 'Activist and artist' Ralph Smith has made a series of posters showing the face of a person with autism and, beneath, the line: 'We are autistic adults.' Each has a different slogan across the middle. One reads: 'Cure is an act of hatred.' Another says: 'Martin cured himself. We miss him.'

But how can wanting to do something so apparently benign as cure someone with autism gener-

ate such hostility? The first step to understanding the powerful feelings on display here is to be clearer about what autism is. For the charities, desperate parents and medical researchers, it is a cruel and mysterious twist of fate and genes that blights lives. From this perspective, campaigning and working towards a cure is a fine example of altruism. As to what goes wrong, most of the current theories concentrate on what is missing – autistics don't have a theory of mind, they have a weak executive function: they can, as it were, see the individual trees but not the whole wood.

I found a good example of this view in the prestigious journal *Science*, in a piece entitled: 'Autistic brains out of synch?' Drawing on brain scans of people with autism, the article proposed that the problem lies with abnormal communication between different regions of the brain, rather than with regions that are faulty in themselves.

Autism, explained the authors, was accompanied by 'diverse deficits and occasional talents'. Sufferers have 'serious shortcomings in reasoning'; 'they memorise facts easily but find complex concepts elusive'. But now that high-tech imaging is able to show exactly why autistic brains don't work so well, there were 'abnormalities in volume' and 'oddities in organisation' and the 'neural events that plan actions may not be fully intact'.

A few months ago, I might have read the article and thought it interesting but unremarkable. Obviously there is something wrong with autistics' brains and maybe finding out exactly what it is can help them. But, sensitised by the autism activists, I was intrigued by a passage reporting that some brain areas had 30 per cent more white matter. The significance of this is that white matter is the brain's equivalent of insulation around an electric cable; more of it makes the messages travel faster.

'This suggests,' wrote the authors, 'that individual brain regions – particularly the prefrontal cortex devoted to complex processing – may well have hyper-efficient internal communications.' And that was that; no further discussion of evidence for a possible superior ability.

This tendency to see only damage in autistic brains has been fiercely attacked by Michelle Dawson, an autism radical who works at the University of Montreal. She has compiled evidence to show that people diagnosed with autism are superior to 'normals' in a number of ways. They are better at doing visual searches, better at remembering auditory pitch and can generally process information faster. Perhaps most interestingly, they are much less likely to have false memories.

Most of us are bad at actually seeing what is in front of us. Because our attention is always flitting from one thing to another, we tend to fill in the gaps with what we assume is there. That's why eyewitness reports are so unreliable. However, examples of the way autistic brains can function more efficiently are generally ignored by researchers. 'It's because "autism advocates" [people campaigning to find a cure] have no concept of autistics succeeding as autistic people,' says Dawson. ▶

WE HAVE A MENTAL SPACE LIKE A FLAT RIVER BED. AUTISTICS CREATE A GRAND CANYON...

◀ ‘The underlying assumption is that autistic traits are destructive, useless and wrong.’

But there seems an air of special pleading about all this. In fact, everyone knows that some autistic people can have remarkable abilities and, fascinating as the differences between autistic and non-autistic brains may be, the bottom line is that many people with autism seem not to function at all well, to be deeply unhappy and disturbed and to need a lifetime of special care. How can it be wrong to try to help them?

What I needed was an insight into what it is like to be in an autistic’s brain. Why do they feel the need to perform repetitive movements, why is social contact so hard, why do they get so furious and distressed, and how can you claim that functioning in that way is just as valid as the way in which the rest of us function? I got some answers from Mike Lesser and Dr Dinah Murray, two British academics who have collaborated on autism research for 15 years.

Mike Lesser has a number of autistic characteristics, but is able to work in the everyday world, albeit often with difficulty. Just how hard life could be even for him soon became clear as we talked in his comfortably cluttered London study. He hadn’t gone to the Autscope conference, ‘because it would have been too much. I’d have just sat in my room reading a textbook, because people think it is a bit odd doing that in the lecture hall.’

Fearsomely bright, he describes himself as a mathematical philosopher and computer expert. He is also passionate and charming, apparently perfectly prepared to reveal just how tough social situations can seem to him. Curled up in an armchair, he would often scrunch up his eyes when I asked a question, sometimes burying them in his hands to block out any competing stimuli. When I’d finished, he looked at me again. Sometimes his eyes would be alive and he’d cry, enthusiastically, ‘Good question!’ and launch into a clear and intense reply. At other times his eyes were wide



Light fantastic: teacher Lynda Middlemiss works intensively with pupil Joseph Bullen at the Hollies in Cardiff



with alarm and he’d say with a note of real distress: ‘I don’t know what you mean,’ and I imagined him mentally clicking through an infinite list of possibilities thrown up by some ambiguity on my part.

‘If there is more than one other person in the room, I don’t know how to allocate my attention,’ he explained. ‘Dinah doesn’t count, as she and I work as one person, but if there was someone with you, I couldn’t cope. I can manage for a short period, but it’s never easy because it takes so much effort to stay at the right level. I have a tendency to plunge into profound technicalities. Someone will say, “It’s a nice day,” and in no time I’ve gone into cold fronts and millibars.’

When the going gets too tough, though, Mike has a way of dealing with it. ‘I bang my head on the door. It certainly makes people stop talking at once.’

What finally allowed me to understand just why social interactions are such a minefield for him was the theory set out in a paper he and Dinah published this summer with autism activist Wendy Lawson in *Autism*. Rather than seeing autism as a pathology, the result of faulty brain wiring, the paper subtly redefines it in terms of a basic mental function that we are all familiar with – attention.

The rest of us – known as NTs in autistic circles, meaning ‘neurologically typical’ – know what it is like to concentrate hard on something – sport, playing music, writing – but can instantly switch our attention. We do it all the time. Arriving in the office, you notice that the boss isn’t in yet and that the windows are dirty. A colleague says, ‘Hi’ and you notice she’s wearing particularly high heels, you glance

through a memo, take a phone call. That’s the state Mike calls polytropic; many interests, each one mildly arousing, that your attention flits between.

‘In our theory, we emphasise that attention is a limited mental resource,’ says Mike. ‘You can spread it about over a lot of things or you can concentrate it on one thing, but you can’t do both.’ The autistic way of using attention is to put all your mental eggs into one basket; this is monotropic attention. The result is what he calls ‘the attention tunnel’ or, to borrow an image from geography ‘a deep basin of attraction’. Most of us have a mental space that is like a river delta – fairly flat with lots of connecting channels, only the water (information) is flowing both ways. The autistic style is to create psychological Grand Canyons.

It quickly becomes clear that the effect of this on social interactions can be devastating. Imagine you come into the office and your attention is caught by the dirt on the windows. At once you may plunge into a deep basin of attraction; you concentrate on the shapes it creates, maybe begin to work out the area it covers as a proportion of the whole window. But then a colleague says ‘Hi’ and you are yanked out of the basin only to fix on her high heels.

The theory makes sense of another of the classic features of autistic behaviour known as ‘meltdown’ or ‘discombobulations’. ‘It’s a state where you are temporarily robbed of the capacity to think or act effectively,’ says Dinah. ‘It happens because a monotropic system is prone to bottlenecks and extreme responses.’ It’s a state that she is all too horribly familiar with. When you are down in an attention tunnel you will miss many of the peripheral cues about what is happening around you, so events constantly come up and blindside you. In a fast-changing environment, and that might be a party or a supermarket, the effect can induce overwhelming panic and meltdown.

Dr Dinah Murray is another academic high-flyer, with three degrees including linguistics and philosophy, who has published widely on autism and been a tutor at Birmingham University; she’s also married with three children. Earlier this year, she identified herself as an ‘autistic cousin’ in a book she edited, entitled *Coming out Asperger*. Although she obviously functions well in the everyday world, on psychometric tests she scores somewhere between a typical female and ‘a person likely to have autism-spectrum diagnosis’. And she knows all about meltdown. ‘I’m generally good-natured,’ she says, ‘and I score as normal on tests for “reading the mind in the eyes”, but at times I flare up in an extreme of rage and panic, and a desire to avoid those states has certainly had a big effect on my life.’ Ironically, one of the things that makes those states even more difficult is the uncomprehending response of the NTs around her. In the lecture she gave at Autscope, she described how she wanted to say to people at those times: ‘This is not about you. Please do not sit there misattributing my emotions.’ Yet again it looks as though the problem for people on the autistic spectrum is not so much that ▶

'AUTISTICS CAN GET EXTREME JOY FROM SIMPLY WATCHING SUNLIGHT FILTER THROUGH TREES'

◀ they are unable to imagine what is going on in other people's minds, but that NTs fail to work out what is happening in autistic minds.

As well as making some of the negative sides of autism more comprehensible, the monotropic theory gives an insight into some of the positive sides and suggests why simply to regard it as a handicap is to miss so much. 'It can give you an extraordinary zest for life,' says Rita Jordan, professor in autism studies at Birmingham University. 'You can get extreme joy from just being in a room with a high ceiling, or watching sunlight filtering through trees.'

More controversially, the monotropic theory suggests why the autistic brain organisation may have allowed various scientific greats – Newton and Einstein are regularly mentioned – to make their imaginative leaps. 'Instead of building up a network of huge numbers of links between shallow points of interest,' says Mike, 'the monotropic brain has fewer links between much deeper interests. That's what makes intellectual breakthroughs possible.'

'Actually, this idea about monotropism is not a model of autism,' Mike goes on, 'it's really a theory about human beings, in which autism has a natural role.' Its central claim is that many of the features that are supposed to mark out autistics as a group with a form of brain damage are actually just down the far end of a trait we all share – attention. So autistic wiring is not necessarily more pathological than variations in IQ or emotional robustness.

Experts in the mainstream often object that this is special pleading. 'Most of the people committed to this sort of view of autism are at the high end of performing,' says Professor Anthony Bailey of Oxford's psychiatry department, which next year will look at the brains of autistic people with a new, fast £2.7m MEG scanner that can catch brain activity

DEFINITION AND TREATMENTS

The Autism Society of America (ASA) says that one in 166 people are somewhere on the autistic spectrum, and that in the States there is one autism diagnosis every 20 minutes. About 75 per cent of those affected are males. An estimated 534,000 people in Britain have an 'autistic-spectrum disorder'. The official definition of autism, first identified in 1943, includes: 'communication problems, difficulties socialising and a lack of imagination'. But there is no single, clearly identifiable set of behaviours that defines it. Autism may also include a 'bewildering range of strange disorders, obsessions and visual problems'. Some of the therapies used to treat it include: ABA (Applied Behaviour Analysis), sensory integration therapy, AIT (Auditory Integration Therapy), GFCF (Gluten-Free/Casein-Free) and anti-candida diets, Irlen lenses, herbal remedies and psychotropic drugs.

almost in real time. 'What it ignores is those who are mute and handicapped or suffering from epilepsy.'

It's a charge that goes to the heart of this bitter and often emotional disagreement, and raises one of the oldest debates of all: are we the result of nature or nurture? Do genetic mutations account for the different wiring of the autistic brain, which then shows up as disturbed behaviour, or does the way autistic people are often treated contribute to the problem? The results of brain scans can be misleading, say the radicals: the scan of a blind person's brain would show an expansion of areas devoted to touch, but that is not the cause of blindness but the result. Both sides would agree that nature and nurture are inextricably intertwined, but they disagree on what research should focus on. Do you concentrate on nature, looking for differences in brain structure and trying to identify the genes that account for them, or do you concentrate on nurture, creating an environment that allows autistic people to function as well as possible?

By concentrating on the serious disabilities of autism and trying to link them to the hardwiring of brain and genes, say the radicals, the mainstream misses something very important. It leads them to dismiss people like Mike and Dinah, who can function in the world, as not having anything relevant to say about what it is like to be 'really' autistic, ie mute and handicapped. But if the monotropic theory has really captured something of the

experience of autism, then the likes of Mike and Dinah can act as guides to a mental world shared by more than 500,000 people; a world that the rest of us NTs seem to find very hard to comprehend.

Dinah believes a major reason she can function as she does stems from how she was brought up, as she makes clear in *Coming Out Asperger*. As a child, she spoke very early, was reading by two and was clearly highly intelligent – but also a bit odd. 'I did a lot of things that today might well attract a diagnosis of Asperger's,' she says. Some social interactions would trigger a meltdown, she spent a lot of time looking at the world through her fingers, responded very strongly to smells and was often accused of being unaware of people's needs.

'But I was a member of a distinguished family within an intellectual elite who could be eccentric to their heart's content,' she says. 'So I was supported and encouraged to feel good about myself. Small differences in my temperament or circumstances could have caused a major shift in the way I behaved. So I acknowledge my kinship with all those autistics judged to be low-functioning.'

The Dinah that might have been would also have been marked out by her 'stimming' – those repetitive movements such as rocking or pacing, that are regarded as a classic sign of severe autism. Mike, however sees stimming quite differently. 'Rhythmic movements are something everyone finds rewarding,' he says. 'What about marching

or foot stamping at football matches or the Mexican wave? They are all forms of mass stimming, yet nobody thinks football fans are disordered. Well, not in an autistic way.'

But even if you accept that people's autistic rights need to be respected, and that the way their brains are wired has its own intrinsic value, you are

ARE MORE PEOPLE BECOMING AUTISTIC?

An intense academic debate is currently under way about whether or not more people are developing autism. Certainly many more people are being diagnosed with it. In the Seventies, it was estimated to affect four to five people in 10,000; now the figure is around 40 to 60 per 10,000. Two years ago, health authorities in California announced that the number of people receiving health or education services for autism has increased by 600 per cent in 16 years. Those blaming environmental factors, such as the MMR vaccine, used this as supporting evidence. However, this view was recently challenged by a *New Scientist* article which points out that the increase may be due to more people being diagnosed. Because there is no objective biochemical test for autism, one suggestion is that many of those previously diagnosed as 'mental retards' are now diagnosed as autistic.

left with the problem that they have to live in the world as it is. 'Day-to-day life for an autistic,' remarked Mike, 'is like having to work a computer for the first time without a manual and with a help desk that speaks a foreign language.'

As a result of their inability to read those fleeting, ambiguous social signals the rest of us barely notice, Mike, Dinah and most other high-functioning autistics have to develop the analytical skills of an anthropologist, painstakingly decoding the cultural norms of an unfamiliar tribe. 'A lot of being autistic is not fun, certainly not for yourself and not for others,' says Dinah. 'It wasn't until I was 50 that I realised if I said I wanted something, people felt they should get it for me. I thought that would only apply if I was in authority over them.'

Our conversation frequently circled around the fact that, given a degree of understanding and conditions that fit their mental style, people with autism can function well. 'About 50 years ago,' said Mike, 'if you had a twisted or deformed foot, surgeons would cut the muscles so that it would fit the shoes they had. What we want is a shoe that fits us.'

Unfortunately, our world of multi-tasking, job flexibility, retraining and information overload isn't moving in that direction. 'Western culture is very unfriendly to people of a monotropic disposition,' remarked Dinah. 'Other cultures have different ways of handling people with different dispositions. Some older, eastern cultures may still have ▶

‘RHYTHMIC MOVEMENTS ARE SOMETHING WE ALL FIND REWARDING – LIKE MARCHING’

◀ niches where autistic people could thrive: social groups where idle chat was generally despised, change was rare, ritual pervasive and one day succeeded the other in a predictable pattern with minimum risk of sensory overwhelm. I remember someone talking about growing up in the Yemen, where obsessive intellectuals – autodidacts – didn’t have to go to school. Instead, people tied their shoe laces, buttoned their shirts correctly and made sure they ate. They only had to learn how to do one job.

‘Maybe that’s why autism is showing up more. Even 50 years ago there were more niches for people with quite severe autism – there were craftsmen who would work in one place all their life, hill farmers or even monks. Although I did know one autistic friend who joined a monastery, but he had to leave because he found the monks too sociable,’ she said, roaring with laughter.

But there is one aspect of the modern world that has the power to transform the lives of many people diagnosed with autism: the computer. Using a keyboard avoids many of the problems associated with face-to-face communication; there are children in autism-friendly surroundings who communicate via a keyboard before they learn to talk; older autistics who never mastered speech have taken to putting their words on screen with a vengeance. The internet has been inseparable from



Dr Dinah Murray, academic and ‘autistic cousin’, believes other cultures ‘still have niches where autistic people could thrive’

the rise of the autistic activists and dozens of websites now describe their inner worlds and set out their demands. Autistic people are at home in the virtual world, which is why much of the research for this article was conducted on line.

Dinah is advising on a computer project for autistic children, Reactive Colours, based at Cardiff

University. ‘It’s a program that plays to the kids’ strengths. You can do almost anything on the keyboard and something happens,’ says Dinah. ‘But it is all contained – it’s not suddenly going to change and bite you. We’ve had kids who were out of control and not attending to anything, quietly taking turns to play on it. Teachers love it.’

Shocking and unreasonable as the autism activists seemed at first sight, they are really only bringing a medical backwater up to speed. In our personal relationships, in schools, at work, we all expect a degree of consensus and to have our own needs and wants taken into account. Patient groups in many other fields expect to have a say in the services provided and how research is done. Autism presents a challenge to this trend, not so much, it turns out, because the people involved don’t have a sense of our minds, but because we are very bad at reading theirs. More and more of them are trying to explain what’s going on with them, and what they want. Shouldn’t we be listening? **OM**

Links for further reading and information

www.gettingthetruthout.org aims to show the reality behind stereotypical images of autism.

www.autismandcomputing.org.uk is Mike and Dinah’s site. It ‘aims to explore ways of minimising the effects of a disabling society on people disposed to monotropism’.

www.nas.org.uk is the UK National Autistic Society’s website. It ‘exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services’