

Autistic and proud

ROY, a high-functioning 28-year-old autistic with a blond military buzz cut and a wide disarming grin, lives on society's edge. At his dojo in Takoma Park, Maryland, where he has lived for the past six-and-a-half years, he leads an essentially monastic existence immersed in his two passions: martial arts and Buddhism. For Roy, who didn't reveal his last name, contact with the outside world has to have a purpose. He agreed to an interview only because he felt his message might be helpful to others. "It's OK not to be interested in socialising, to live quietly on the borders of society," he says. "It's OK to be alone."

Roy has good reason to want his voice heard. With autism diagnoses rising steadily, talk of an "epidemic" and a growing search for a cure, Roy feels threatened. "I feel stabbed when it comes to 'curing' or 'treating' autism," he says. "It's like society doesn't need us."

Many autistic people are starting to agree. They have had enough of being treated as a medical problem, arguing that autism is not a disease that needs to be cured but just a normal part of human diversity. This emerging "autistic rights" movement hopes to launch an international campaign akin to Gay Pride, encouraging autistic people everywhere to embrace their "neurodiversity", and persuading wider society to accept them as they are.

Autism's self advocacy movement began in the early 1990s, though for obvious reasons – autism is a neurological disorder that affects ability to communicate and socialise – the movement has been slow to acquire momentum. "An [autistic] friend of mine says that organising autistics is like herding cats," says Valerie Paradiz, an autism rights campaigner who runs the ASPIE (Autistic Strength, Purpose and Independence in Education) School in Boiceville, New York. However, she says, "we are at a wonderful turning point where all these isolated grass-roots efforts are beginning to congeal." This week, on 18 June, the movement will find its fullest expression yet with the first annual Autistic Pride Day. The slogan: "acceptance not cure".

The event is the brainchild of Aspies For Freedom (AFF), a small web-based group with about 440 members. Co-founders Amy Roberts, 35, and Gareth Nelson, 17, both have Asperger's syndrome. "We feel autism is part of the individual, not a disease that

This week sees the first ever Autistic Pride Day. **Bijal Trivedi** meets the activists who want acceptance, not a cure

someone 'has'," says Nelson. "If more focus was placed on giving children tools to cope with the NT [neurotypical or non-autistic] world rather than trying to change them, that would benefit autistics a lot."

But the notion of autistic rights doesn't sit comfortably with many people whose lives are affected by autism. "The bottom line is I want to help my kid," says Peter Bell, chief executive of the LA-based foundation Cure Autism Now and the father of a 12-year-old autistic boy. Many parents echo his sentiments, especially those who have severely autistic children. They too feel threatened, worrying that the autistic rights movement will oversell the gifts conferred by autism and jeopardise funding for care and research.

Autism, or more accurately the autism spectrum disorders (ASD), encompass a group of three developmental problems – autistic disorder, Asperger's syndrome (or high functioning autism) and pervasive developmental disorder not otherwise specified (PDD-NOS), sometimes called "mild" or "atypical" autism.

Individuals across the spectrum find facial expressions and body language difficult to interpret and imitate, and language and intonation tough to comprehend and even harder to master. Some dislike human touch and social interaction. For others life is made unbearable by severe sensory sensitivities, such as fluorescent lighting and ringing cellphones. Many are locked into rigid daily routines and repetitive behaviours. The cocktail of symptoms varies wildly from one end of the spectrum to the other. Some children need residential care because they are completely unable to communicate with the world. Asperger's children, on the other hand, might be socially awkward but otherwise independent. Many across the spectrum have mind-boggling talents.

At present there is no cure for autism. The only treatments on offer are a variety of behavioural therapies which aim to teach autistic children how to communicate and learn complex tasks. Other therapies focus on relationships and mainstream social skills. ▶

Gareth Nelson and Amy Roberts are campaigning to have autism recognised as a normal part of human diversity





"In a few rare cases, they say, behavioural therapy for autism borders on human rights abuse"

JOHN ANGELO



Roberts and Nelson say there are simple things that society could do to help autistic people

Together these are commonly believed to be the only way to rescue them from a life of social isolation. Some programmes discourage "stimming" – self-stimulatory behaviours that many autistics use, often involuntarily, as calming tools.

But Roberts and Nelson say that coaching children to repress their natural behaviour in favour of mainstream activities such as making eye contact, hugging and socialising is the wrong approach and can cause low self-esteem and depression. In a few rare cases, they say, behavioural therapy even borders on human rights abuse, incorporating electric shock treatments, forced holding and other punishments.

Nelson says it is possible to stop stimming, but it is stressful, draining, and doesn't really help. "Any behaviour can be stopped with enough will power, but sitting in a classroom focusing on 'don't stim' rather than focusing on the work is obviously harmful."

"People have the impression that a child with autism is totally trapped without therapy," adds Roberts. "That is nonsense – many develop skills at a later age."

Aspies For Freedom believe they have their own techniques for levelling the playing field between autistics and NTs. Several interviews for this article, for example, were conducted

online in chat rooms, which many autistic people prefer to phone calls or face-to-face contact. There are other things that society could do, such as provide spaces with non-fluorescent lighting for those with sensory problems. As for harmless behaviours such as involuntary tics like hand flapping or humming, NTs should learn to tolerate them.

"Sadly, the negatives that I experience are generated by other people," says Roberts. "People often are critical of the fact that I show very little expression – so they assume I must be miserable or stern. But it is just my face."

Another of the movement's gripes is that social workers often discourage autistic people from having children because of the risk of passing on the trait, says Roberts. Nelson, Roberts and others fear that this type of pressure, coupled with the possibility of prenatal genetic testing (*New Scientist*, 14 May, p 15), will drag society into the murky zone of eugenics. "We are a minority, but we have the right to have kids like us," says Roberts.

Although no definitive genetic or chemical test exists for autism, many scientists believe that one is possible. Autism has the highest known heritability of any complex neurological disease, according to neuroscientist Pat Levitt, director of the Vanderbilt Kennedy Center for Research on

Human Development in Nashville, Tennessee. Twin studies have shown that when one member of the pair has autism or a related condition, there is an approximately 70 per cent chance of the other twin being autistic too. This is a higher proportion than schizophrenia, with a 40 per cent chance, and depression, with a 25 per cent chance. Several chromosomes have shown associations with autism, though no specific genes have been found.

There are also clues to where a cure might come from. Researchers have made progress identifying anatomical differences between autistic and non-autistic brains. In general, children who develop autism have smaller brains at birth but unusually large brains by age 2 or 3. "This might suggest that brain growth in autistic children is peaking earlier," says Levitt, who also chairs Cure Autism Now's scientific advisory board. One theory is that this accelerated development freezes certain connections too early, interfering with learning, language and communication.

Another study implicates the enlargement of a brain region that links regions of the cortex and is vital for integrating and processing sensory information. Neuroscientists have also discovered that autistic people have elevated numbers of microglial cells and astrocytes in their brains. These cells play a role in the neuroimmune response and trigger inflammation.

Defining disease

While no one disputes that autistic people have unusual brain architecture, whether these changes actually constitute a disease, and hence need a "cure", is hotly debated.

It depends on how you define a disease, says Arthur Caplan, director of the University of Pennsylvania Center for Bioethics. What makes something a disease rests heavily on society, culture and whether there is a chemical that can manipulate the condition. Erectile dysfunction, for example, became a disease overnight. "Before it was something that people just accepted, then there was a pill, and then it became a disease," says Caplan.

One definition of disease is that it destroys your ability to function – to live independently, hold down a job, feed and groom yourself, and get around. Any disorder that inhibits these activities, which is certainly true in most cases of autistic disorder, is robbing a person



A cure for autism would be a blessing for some, but mild forms can enhance skills such as music and maths

of an acceptable quality of life and should be treated, Caplan believes. "I've seen [autistic] kids in institutions who can't tolerate the world," he says. "Everything sends them into a screaming rage. Not curing them would be a tragedy." At the other end of the spectrum, however, Asperger's isn't dysfunctional, says Caplan. It may even enhance some abilities such as mathematics, computer skills and music.

Autism activists are not opposed to all interventions. AFF is in favour of "therapies that are autism friendly", which essentially means anything that doesn't punish autistic behaviour or suggest that it is inherently wrong. And there are signs that this "autism friendly" approach is taking root.

One programme is being tested by Rebecca Landa, director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute in Baltimore, Maryland. She is conducting early diagnosis studies and 10 early intervention trials, each involving five children. Kids begin the programme at just 24 months – a year earlier than most autism interventions. Two-and-a-half hours a day, four days a week for six months they

are exposed to a range of "autism friendly" teaching methods.

Preliminary results are encouraging. "We have seen dramatic improvements in language and communication," says Landa. Peering into a class, it is remarkable how normal everything seems as five 2-year-olds toddle around the classroom with the instructors. One of the few clues that this class is special is that every few minutes the children are asked to check their schedules – a strip of Velcro on the wall with pictures of activities: music, snacks, circle time, play and work. The pictures lead the children to their next activity, easing transitions, which are often a source of great anxiety for them.

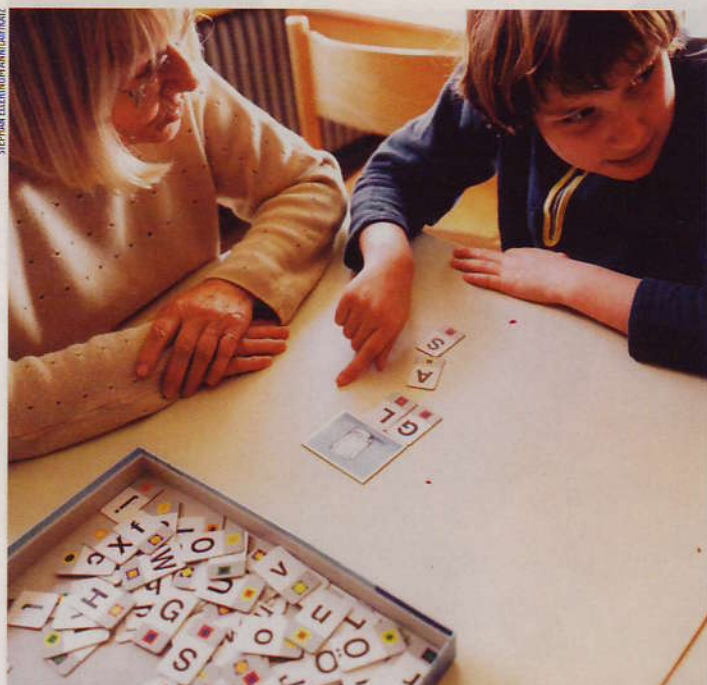
In a scene that seems absurdly orderly, the five children sit around a U-shaped table, armed with picture cards. One of the children, Sean Kelly, a lively toddler with a mass of bouncy brown curls, requests more raisins with a card. "For the first time he understands that communication has a purpose," says his mother Debby Kelly as she watches through an observation window.

Sean is five months into the programme. When he started he barely spoke, didn't have many words and couldn't follow instructions. "Now he has sentences, lots of words – more than I can count," says Kelly. "He is interested ▶

"Symptoms of autism vary widely. Many have mind-boggling talents"

"For some families living with autism, the philosophy of acceptance not cure will never catch on"

STEPHAN ELLERMAN/AMANTAUKE



Activists welcome teaching methods that do not punish or stigmatise autistic behaviour

in socialising. He gives more eye contact. He used to upset easily, throwing a fit if an activity changed, but now he's doing better. It has made a big impression on him."

Another pioneer of autism-friendly intervention is the ASPIE School in Boiceville, New York, where 15 students aged 12 to 16 study autism advocacy and "NT culture". "We encourage learning social skills by choice," says Paradiz, founder and director of the school. "We deconstruct why [NT] people make eye contact, for example, and show how these behaviours will be useful for students who want to live independently and get a job in the NT world where they are a minority."

Then there's Autreat, a retreat-style conference run by autistic people for autistic people that emphasises "positive living with autism". Paradiz attends annually with her Aspie son Elijah and finds it exhilarating. Most of the presenters are autistic, discussing themes such as "how to deal with your NT parents". They also celebrate the deep interest many autistics have in a subject area or activity – what are known as perseverations. Many autistics cite these as their greatest gift,

and see them as the most compelling reason to resist a cure.

Temple Grandin, an animal scientist at Colorado State University in Fort Collins who has gained celebrity status in the autistic community, says perseverations are a gift if they can be channelled into a career. Grandin exploited her perseveration on cattle squeeze chutes to become a leading designer of livestock facilities.

Going solo

For Roy, his desire for solitude and interest in Buddhism are tough to spin into a career. But there have always been spiritual people who have characteristics of Asperger's and autism and have lived in silence. "If they had had a monk booth on career day," says Roy, "that would have been perfect for me."

Few conversations about the "gifts of autism" pass without mention of some of the spectrum's supposed members: Albert Einstein, Andy Warhol and Michelangelo have all been posthumously diagnosed with ASD. These intellectual icons

are summoned up whenever the talk turns to developing a genetic test for autism, arguing that prenatal testing of this type would erase such genius.

"Give parents the opportunity to select among embryos to avoid the chance of autism, and a lot of them are going to take that even though Asperger's, the mildest form of autism, would have given them a child they would have been amazed by," says Caplan.

Not everyone, however, is so enamoured of the movement. Many parents of autistic children point out that autism rights are all well and good for the high-functioning autistics and Aspies who make up the bulk of the movement. But for many autistic people, the idea of "positive living with autism" is meaningless.

Carina Schmidt's son has autistic disorder and requires round-the-clock attention. His condition is so severe that he required a 10-month stay at the Kennedy Krieger Institute to break some of his self-harming habits. She is adamant about doing everything possible to help her son, who now lives in a group home in Rockville, Maryland. She also supports the development of prenatal tests for autism. "If my son could be cured today I would say 'yes'," she says. "My family has suffered like there is no tomorrow – that's why we choose to have no more kids."

Other parents are more ambivalent. "I do understand what they [AFF] are saying," says Kelly. "Autism is not a disease. And autistics do give great gifts to the world." Even so, she chose to put Sean into therapy. "I know the world and I want him to enjoy his life, which will be harder unless he has the skills to communicate."

Just how far the autistic pride movement can go remains to be seen. According to Roberts and Nelson, Autistic Pride Day will start small. But then, so did Gay Pride.

For some families, however, "acceptance not cure" will never catch on. Schmidt says that she will continue seeking help for her son. And she is sure he wants her to. "I can see my son wants to be normal," she says. ●

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