

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 LANGRISH



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