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## How About Not 'Curing' Us, Some Autistics Are Pleading

By AMY HARMON

BOICEVILLE, N.Y. — Jack Thomas, a 10th grader at a school for autistic teenagers and an expert on the nation's roadways, tore himself away from his satellite map one recent recess period to critique a television program about the search for a cure for autism.

"We don't have a disease," said Jack, echoing the opinion of the other 15 boys at the experimental Aspie school here in the Catskills. "So we can't be 'cured.' This is just the way we are."

From behind his GameBoy, Justin Mulvaney, another 10th grader, objected to the program's description of people "suffering" from Asperger's syndrome, the form of autism he has.

"People don't suffer from Asperger's," Justin said. "They suffer because they're depressed from being left out and beat up all the time."

That, at least, was what happened to these students at mainstream schools before they found refuge here.

But unlike many programs for autistics, this school's program does not try to expunge the odd social behaviors that often make life so difficult for them. Its unconventional aim is to teach students that it is O.K. to "act autistic" and also how to get by in a world where it is not.

Trained in self-advocacy, students proudly recite the positive traits autism can confer, like the ability to develop uncanny expertise in an area of interest. This year's class includes specialists on supervolcanoes and medieval weaponry.

"Look at Jack," Justin pointed out. "He doesn't even need a map. He's like a living map."

The new program, whose name stands for Autistic Strength, Purpose and Independence in Education — and whose acronym is a short form of Asperger's — is rooted in a view of autism as an alternative form of brain wiring, with its own benefits and drawbacks, rather than a devas-

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# Try Not 'Curing' Us, Some Autistics Say

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tating disorder in need of curing.

It is a view supported by an increasingly vocal group of adult autistics, including some who cannot use speech to communicate and have been institutionalized because of their condition. But it is causing consternation among many parents whose greatest hope is to avoid that very future for their children. Many believe that intensive behavioral therapy offers the only rescue from the task of caring for unpredictable, sometimes aggressive children, whose condition can take a toll on the entire family.

The autistic activists say they want help, too, but would be far better off learning to use their autistic strengths to cope with their autistic impairments rather than pretending that either can be removed. Some autistic tics, like repetitive rocking and violent outbursts, they say, could be modulated more easily if an effort were made to understand their underlying message, rather than trying to train them away. Other traits, like difficulty with eye contact, with grasping humor or with breaking from routines, might not require such huge corrective efforts on their part if people were simply more tolerant.

Spurred by an elevated national focus on finding a cure for autism at a time when more Americans are receiving autism diagnoses than ever before — about one in 200 — a growing number of autistics are staging what they say amounts to an ad hoc human rights movement. They sell Autistic Liberation Front buttons and circulate petitions on Web sites like neurodiversity.com to “defend the dignity of autistic citizens.” The Autistic Advocacy e-mail list, one of dozens that connect like-minded autistics, has attracted nearly 400 members since it started last year.

“We need acceptance about who we are and the way we are,” said Joe Mele, 36, who staged a protest at Jones Beach, on Long Island, while 10,000 people marched to raise money for autism research recently. “That means you have to get out of the cure mind-set.”

A neurological condition that can render standard forms of communication like tone of voice, facial expression and even spoken language unnatural and difficult to master, autism has traditionally been seen as a shell from which a normal child might one day emerge. But some advocates contend that autism is an integral part of their identities, much



Tim Shaffer for The New York Times

“Behaviors are so often attempts to communicate,” says Jane Meyering, an autistic woman.

more like a skin than a shell, and not one they care to shed.

The effort to cure autism, they say, is not like curing cancer, but like the efforts of a previous age to cure left-handedness. Some worry that in addition to troublesome interventions, the ultimate cure will be a genetic test to prevent autistic children from being born.

That would be a loss, they say, not just for social tolerance but because

## The differently wired take on those who would rid them of their tics and traits.

autistics, with their obsessive attention to detail and eccentric perspective, can provide valuable insight and innovation. The neurologist Oliver Sacks, for instance, contends that Henry Cavendish, the 18th-century chemist who discovered hydrogen, was most likely autistic.

“What they’re saying is their goal is to create a world that has no people like us in it,” said Jim Sinclair, who did not speak until he was 12 and whose 1993 essay “Don’t Mourn for Us” serves as a touchstone for a fledgling movement.

At this year’s “Autreat,” an annual spring gathering of autistics, attendees compared themselves to gay

rights activists, or the deaf who prefer sign language over surgery that might allow them to hear. Some discussed plans to be more openly autistic in public, rather than take the usual elaborate measures to fit in. Others vowed to create more autistic-friendly events and spaces.

Autreat participants, for instance, can wear color-coded badges that indicate whether they are willing to be approached for conversation. Common autistic mannerisms, like exceedingly literal conversation and hand-flapping, are to be expected. Common sources of autistic irritation, like casual hugs and fluorescent lighting, are not.

For many parents, however, the autistic self-advocacy movement often sounds like a threat to the brighter future they envision for their children. In recent months, the long-simmering argument has erupted into an online brawl over the most humane way to handle an often crippling condition.

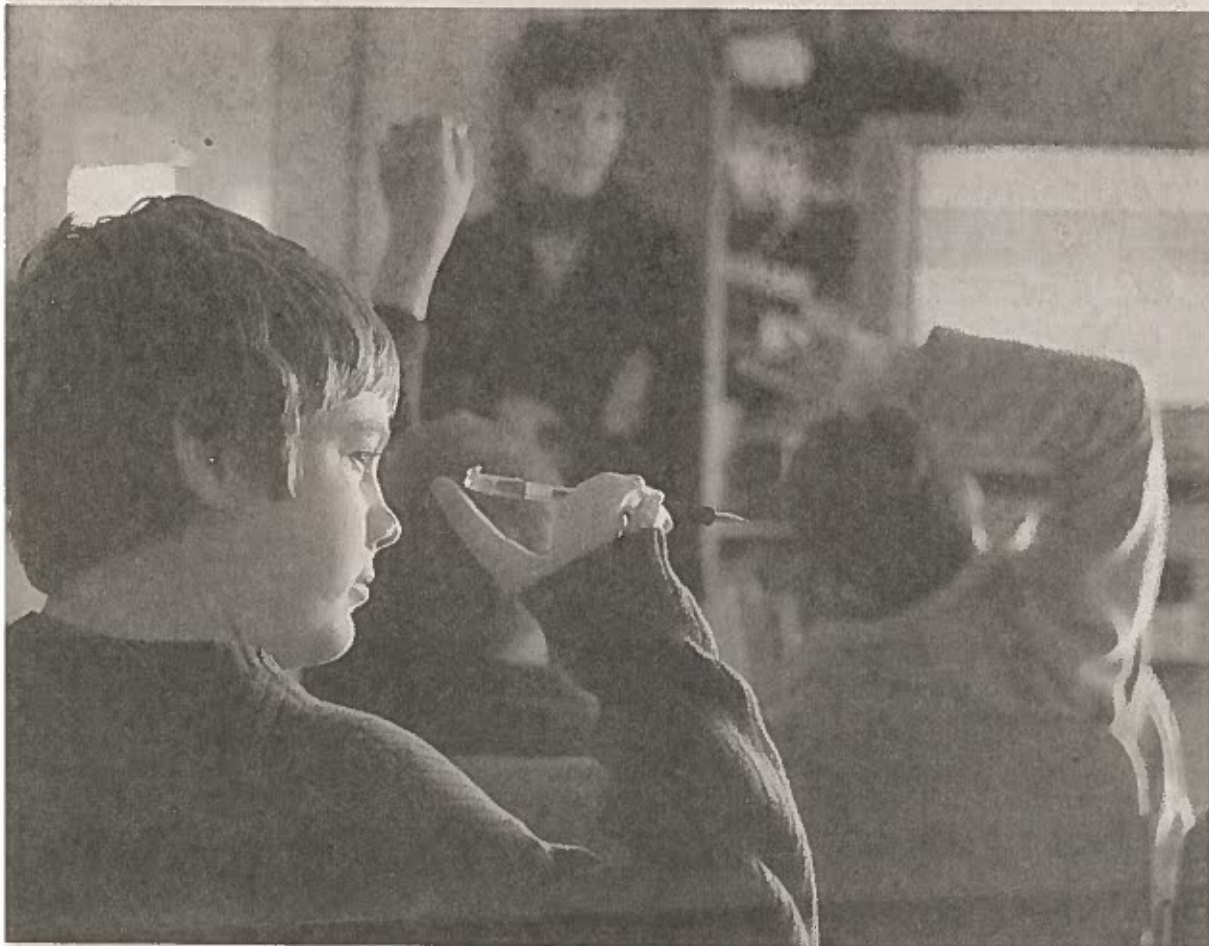
On e-mail lists frequented by autistics, some parents are derided as “curebies” and portrayed as slaves to conformity, so anxious for their children to appear normal that they cannot respect their way of communicating. Parents argue that their antagonists are showing a typical autistic lack of empathy by suggesting that they should not try to help their children. It is only those whose diagnosis describes them as “high functioning” or having Asperger’s syndrome, they say, who are opposed to a cure.

“If those who raise their opposition to the so-called oppression of the autistic would simply substitute their usage of ‘autism or autistic’ with ‘Asperger’s,’ their arguments might make some sense,” Lenny Schafer, publisher of the widely circulated Schafer Autism Report, wrote in a recent e-mail message. “But I intend to cure, fix, repair, change over etc. my son and others like him of his profound and typical disabling autism into something better. Let us regain our common sense.”

But the autistic activists say it is not so easy to distinguish between high and low functioning, and their ranks include both.

In an effort to refute parental skeptics, the three owners of autistics.org, a major Web hub of autistic advocacy, issued a statement listing their various impairments. None of them are fully toilet-trained, one of them cannot speak, and they have all injured themselves on multiple occasions, they wrote: “We flap, finger-flick, rock, twist, rub, clap, bounce, squeal, hum, scream, hiss and tic.”





Tara Engberg for The New York Times

Wilson Meagor, who has Asperger's syndrome, was absorbed with his pen as he waited recently for a screening of "Rainman" at his experimental Aspie school in Boiceville, N.Y. Valerie Paradiz, rear, teaches there.

The touchiest area of dispute is over Applied Behavior Analysis, or A.B.A., the therapy that many parents say is the only way their children were able to learn to make eye contact, talk and get through the day without throwing tantrums. Some autistic adults, including some who have had the therapy, say that at its best it trains children to repress their natural form of expression and at its worst borders on being abusive. If an autistic child who screams every time he is taken to the supermarket is trained not to, for example, he may still be experiencing pain from the fluorescent lights and crush of strangers.

"Behaviors are so often attempts to communicate," said Jane Meyerding, an autistic woman who has a clerical job at the University of Washington and is a frequent contributor to the Autistic Advocacy e-mail discussion list. "When you snuff out the behaviors you snuff out the attempts to communicate."

Perhaps the most public conflict between parents and adult autistics came in a lawsuit brought by several Canadian families who argued that the government should pay for their children's A.B.A. therapy because it

is medically necessary. Michelle Dawson, an autistic woman in Montreal, submitted testimony questioning the ethics of the therapy, which the Canadian Supreme Court cited in its ruling against the families in November.

Ms. Dawson's position infuriates many parents who are fighting their own battles to get governments and insurance companies to pay for the expensive therapy.

"I'm afraid of this movement," said Kit Weintraub, the mother of two autistic children in Madison, Wis.

Ms. Weintraub's son, Nicholas, has benefited greatly from A.B.A., she said, and she is unapologetic about wanting to remove his remaining quirks, like his stilted manner of speaking and his wanting to be Mickey Mouse for Halloween when other 8-year-olds want to be Frodo from "The Lord of the Rings."

"I worry about when he gets into high school, somebody doesn't want to date him or be his friend," she said. "It's no fun being different."

The dispute extends even to the basic terminology of autism.

"I would appreciate it, if I end up in your article, if you describe me as

'an autistic' or 'an autistic person,' versus the 'person with ...,'" Ms. Dawson wrote in an e-mail message. "Just like you would feel odd if people said you were a 'person with femaleness.'"

Ms. Weintraub insists on the opposite. "My children have autism, they are not 'autistics,'" she wrote in her own widely circulated essay, "A Mother's Perspective." "It is no more normal to be autistic than it is to have spina bifida."

Terry Walker, 37, who has Asperger's syndrome, said he was not opposed to the concept of a cure for autism but he suggested that there was a pragmatic reason to look for other options.

"I don't think it's going to be easy to find," Mr. Walker said. "That's why I opt for changing the world around me; I think that does more long-term good."

Quotation of the Day,  
Page 2, every day,  
in the News Summary.  
The New York Times.