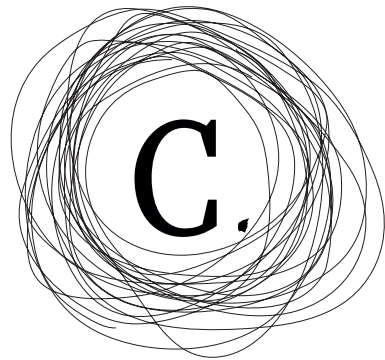




AMANDA BAGGS is at the forefront of a movement that's forcing

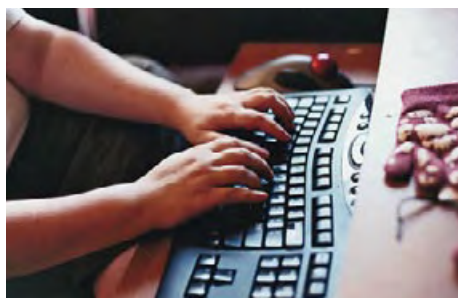
YEAH,  
I'M

# A U T I S T I C.



*You got a problem with that?*

by DAVID WOLMAN



photographs by JESSICA DIMMOCK  
*scientists to reconsider what they think they know about autism.*

1 5 5



**THE YOUTUBE CLIP OPENS** with a woman facing away from the camera, rocking back and forth, flapping her hands awkwardly, and emitting an eerie hum. She then performs strange repetitive behaviors: slapping a piece of paper against a window, running a hand lengthwise over a computer keyboard, twisting the knob of a drawer. She bats a necklace with her hand and nuzzles her face against the pages of a book. And you find yourself thinking: Who's shooting this footage of the handicapped lady, and why do I always get sucked into watching the latest viral video? ¶ But then the words "A Translation" appear on a black screen, and for the next five minutes, 27-year-old Amanda Baggs—who is autistic and doesn't speak—describes in vivid and articulate terms what's going on inside her head as she carries out these seemingly bizarre actions. In a synthesized voice generated by a software application, she explains that touching, tasting, and smelling allow her to have a "constant conversation" with her surroundings. These

forms of nonverbal stimuli constitute her “native language,” Baggs explains, and are no better or worse than spoken language. Yet her failure to speak is seen as a deficit, she says, while other people’s failure to learn her language is seen as natural and acceptable.

And you find yourself thinking: She might have a point.

Baggs lives in a public housing project for the elderly and handicapped near downtown Burlington, Vermont. She has short black hair, a pointy nose, and round glasses. She usually wears a T-shirt and baggy pants, and she spends a scary amount of time—day and night—on the Internet: blogging, hanging out in Second Life, and corresponding with her autie and aspie friends. (For the uninitiated, that’s *autistic* and *Asperger’s*.)

On a blustery afternoon, Baggs reclines on a red futon in the apartment of her neighbor (and best friend). She has a gray travel pillow wrapped around her neck, a keyboard resting on her lap, and a DynaVox VMax computer propped against her legs.

Like many people with autism, Baggs doesn’t like to look you in the eye and needs help with tasks like preparing a meal and taking a shower. In conversation she’ll occasionally grunt or sigh, but she stopped speaking altogether in her early twenties. Instead, she types 120 words a minute, which the DynaVox then translates into a synthesized female voice that sounds like a deadpan British schoolteacher.

The YouTube post, she says, was a political statement, designed to call attention to people’s tendency to underestimate autistics. It wasn’t her first video post, but this one took off. “When the number of viewers began to climb, I got scared out of my mind,” Baggs says. As the hit count neared 100,000, her blog was flooded. At 200,000, scientists were inviting her to visit their labs. By 300,000, the TV people came calling, hearts warmed by the story of a young woman’s fiery spirit and the rare glimpse into what has long been regarded as the solitary imprisonment of the autistic mind. “I’ve said a million times that I’m not ‘trapped in my own world,’” Baggs says. “Yet what do most of these news stories lead with? Saying exactly that.”

I tell her that I asked one of the world’s leading authorities on autism to check out the video. The expert’s opinion: Baggs must have had outside help creating it, perhaps from one of her caregivers. Her inability to talk, coupled with repetitive behaviors, lack of eye contact, and the need for assistance with everyday tasks are telltale signs of severe autism. Among all autistics, 75 percent are expected to score in the mentally retarded range on standard intelligence tests—that’s an IQ of 70 or less.

People like Baggs fall at one end of an array of developmental syndromes known as autism spectrum disorders. The spectrum ranges from someone with severe disability and cognitive impairment to the socially awkward eccentric with Asperger’s syndrome.

After I explain the scientist’s doubts, Baggs grunts, and her mouth forms just a hint of a smirk as she lets loose a salvo on the keyboard. No one helped her shoot the video, edit it, and upload it to YouTube. She used a Sony Cybershot DSC-T1, a digital camera that can record up to 90 seconds of video (she has since upgraded). She then patched the footage together using the editing programs RAD Video Tools,

VirtualDub, and DivXLand Media Subtiter. “My care provider wouldn’t even know how to work the software,” she says.

Baggs is part of an increasingly visible and highly networked community of autistics. Over the past decade, this group has benefited enormously from the Internet as well as innovations like type-to-speech software. Baggs may never have considered herself trapped in her own world, but thanks to technology, she can communicate with the same speed and specificity as someone using spoken language.

Autistics like Baggs are now leading a nascent civil rights movement. “I remember in ‘99,” she says, “seeing a number of gay pride Web sites. I envied how many there were and wished there was something like that for autism. Now there is.” The message: We’re here. We’re weird. Get used to it.

This movement is being fueled by a small but growing cadre of neuropsychological researchers who are taking a fresh look at the nature of autism itself. The condition, they say, shouldn’t be thought of as a disease to be eradicated. It may be that the autistic brain is not defective but simply different—an example of the variety of human development. These researchers assert that the focus on finding a cure for autism—the disease model—has kept science from asking fundamental questions about how autistic brains function.

A cornerstone of this new approach—call it the difference model—is that past research about autistic intelligence is flawed, perhaps catastrophically so, because the instruments used to measure intelligence are bogus. “If Amanda Baggs had walked into my clinic five years ago,” says Massachusetts General Hospital neuroscientist Thomas Zeffiro, one of the leading proponents of the difference model, “I would have said she was a low-functioning autistic with significant cognitive impairment. And I would have been totally wrong.”

**SEVENTY YEARS AGO**, a Baltimore psychiatrist named Leo Kanner began recording observations about children in his clinic who exhibited “fascinating peculiarities.” Just as Kanner’s landmark paper was about to be published, a pediatrician in Vienna named Hans Asperger was putting the finishing touches on a report about a similar patient population. Both men, independently, used the same word to describe and define the condition: *autist*, or *autism*, from the Greek *autos*, meaning self.

The children had very real deficits, especially when it came to the “failure to be integrated in a social group” (Asperger) or the inborn inability to form “affective contact” with other people (Kanner). The two doctors’ other observations about language impairment, repetitive behaviors, and the desire for sameness still form much of the basis of autism diagnoses in the 21st century.

On the matter of autistic intelligence, Kanner spoke of an array of mental skills, “islets of ability”—vocabulary, memory, and problem-solving that “bespeak good intelligence.” Asperger, too, was struck by “a particular originality of thought and experience.” Yet over the years, those islets attracted scientific interest only when they were amazing—savant-level capabilities in areas such as music, mathematics, and drawing. For the millions of people with autism who weren’t savants, the general view was that their condi-

*“If Amanda Baggs had walked into my clinic five years ago,” says neuroscientist*

THOMAS ZEFFIRO,

*“I would have said she had*



tion was tragic, their brainpower lacking.

The test typically used to substantiate this view relies heavily on language, social interaction, and cultural knowledge—areas that autistic people, by definition, find difficult. About six years ago, Meredyth Goldberg Edelson, a professor of psychology at Willamette University in Oregon, reviewed 215 articles published over the past 71 years, all making or referring to this link between autism and mental retardation. She found that most of the papers (74 percent) lacked their own research data to back up the assumption. Thirty-nine percent of the articles weren't based on any data, and even the more rigorous studies often used questionable measures of intelligence. "Are the majority of autistics mentally retarded?" Goldberg Edelson asks. "Personally, I don't think they are, but we don't have the data to answer that."

Mike Merzenich, a professor of neuroscience at UC San Francisco, says the notion that 75 percent of autistic people are mentally retarded is "incredibly wrong and destructive." He has worked with a number of autistic children, many of whom are nonverbal and would have been plunked into the low-functioning category. "We label them as retarded because they can't express what they know," and then, as they grow older, we accept that they "can't do much beyond sit in the back of a warehouse somewhere and stuff letters in envelopes."

The irony is that this dearth of data persists even as autism receives an avalanche of attention. Organizations such as Autism Speaks advocate for research and resources. Celebrity parents like Toni Braxton, Ed Asner, and Jenny McCarthy get high-profile coverage on talk shows and TV news magazines. Newsweeklies raise fears of an autism epidemic. But is there an epidemic? There's certainly the perception of one. According to the Centers for Disease Control, one out of every 150 8-year-old children (in the areas of the US most recently studied) has an autism spectrum disorder, a prevalence much higher than in decades past, when the rate was thought to be in the range of four or five cases per 10,000 children. But no one knows whether this apparent explosion of cases is due to an actual rise in autism, changing diagnostic criteria, inconsistent survey techniques, or some combination of the three.

In his original paper in 1943, Kanner wrote that while many of the children he examined "were at one time or another looked upon as feeble-minded, they are all unquestionably endowed with good *cognitive potentialities*." Sixty-five years later, though, little is known about those potentialities. As one researcher told me, "There's no money in the field for looking at differences" in the autistic brain. "But if you talk about trying to fix a problem—then the funding comes."

*significant cognitive impairment. And I would have been*  
WRONG."



**ON THE OUTSKIRTS** of Montreal sits a brick monolith, the Hôpital Rivière-des-Prairies. Once one of Canada's most notorious asylums, it now has a small number of resident psychiatric patients, but most of the space has been converted into clinics and research facilities.

One of the leading researchers here is Laurent Mottron, 55, a psychiatrist specializing in autism. Mottron, who grew up in postwar France, had a tough childhood. His family had a history of schizophrenia and Tourette syndrome, and he probably has what today

would be diagnosed as attention deficit and hyperactivity disorder. Naturally, he went into psychiatry. By the early '80s, Mottron was doing clinical work at a school in Tours that catered to children with sensory impairment, including autism. "The view then," Mottron says, "was that these children could be reeled back to normalcy with play therapy and work on the parents' relationships"—a gentle way of saying that the parents, especially the mother, were to blame. (The theory that emotionally distant "refrigerator mothers" caused autism had by then been rejected in the US, but in France and many other countries, the view lingered.)

After only a few weeks on the job, Mottron decided the theories were crap. "These children were just of another kind," he says. "You couldn't turn someone autistic or make someone not autistic. It was hardwired." In 1986, Mottron began working with an autistic man who would later become known in the scientific literature as "E.C." A draftsman who specialized in mechanical drawings, E.C. had incredible savant skills in 3-D drawing. He could rotate objects in his mind and make technical drawings without the need for a single revision. After two years of working with E.C., Mottron made his second breakthrough—not about autistics this time but about the rest of us: People with standard-issue brains—so-called neurotypicals—don't have the perceptual abilities to do what E.C. could do. "It's just inconsistent with how our brains work," Mottron says.

From that day forward, he decided to challenge the disease model underlying most autism research. "I wanted to go as far as I could to show that their perception—their brains—are totally different." Not damaged. Not dysfunctional. Just different.

By the mid-1990s, Mottron was a faculty member at the University of Montreal, where he began publishing papers on "atypicalities of perception" in autistic subjects. When performing certain mental tasks—especially when tapping visual, spatial, and auditory functions—autistics have shown superior performance compared with neurotypicals. Call it the upside of autism. Dozens of studies—Mottron's and others—have demonstrated that people with autism spectrum disorder have a number of strengths: a higher prevalence of perfect pitch, enhanced ability with 3-D drawing and pattern recognition, more accurate graphic recall, and various superior memory skills.

Yet most scientists who come across these skills classify them as "anomalous peaks of ability," set them aside, and return to the questions that drive most research: What's wrong with the autistic brain? Can we find the genes responsible so that we can someday cure it? Is there a unifying theory of autism? With severe autistics, cognitive strengths are even more apt to be overlooked because these indi-



“To a remarkable degree, scientists continue to use

viduals have such obvious deficits and are so hard to test. People like Baggs don't speak, others may run out of the room, and still others might not be able to hold a pencil. And besides, if 75 percent of them are mentally retarded, well, why bother?

Mottron draws a parallel with homosexuality. Until 1974, psychiatry's bible, the *Diagnostic and Statistical Manual of Mental Disorders*, described being gay as a mental illness. Someday, Mottron says, we'll look back on today's ideas about autism with the same sense of shame that we now feel when talking about psychology's pre-1974 views on sexuality. “We want to break the idea that autism should definitely be suppressed,” he says.

**M**ICHELLE DAWSON

doesn't drive or cook. Public transit overwhelms her, and face-to-face interaction is an ordeal. She was employed as a postal worker in 1998 when she “came out of the closet” with her diagnosis of autism, which she received in the early '90s. After that, she claims, Canada Post harassed her to such a degree that she was forced to take a permanent leave of absence, starting in 2002. (Canada Post says Dawson was treated fairly.) To

fight back, she went on an information-devouring rampage. “There's such a variety of human behavior. Why is my kind wrong?” she asks. She eventually began scouring the libraries of McGill University in Montreal to delve into the autism literature. She searched out journal articles using the online catalog and sat on the floor reading studies among the stacks.

Dawson, like Baggs, has become a reluctant spokesperson for this new view of autism. Both are prolific bloggers and correspond constantly with scientists, parents' groups, medical institutions, the courts, journalists, and anyone else who'll listen to their stories of how autistics are mistreated. Baggs has been using YouTube to make her point; Dawson's weapon is science.

In 2001, Dawson contacted Mottron, figuring that his clinic might help improve the quality of her life. Mottron tried to give her some advice on navigating the neurotypical world, but his tips on how to handle banking, shopping, and buses didn't help. After meeting with her a few times, Mottron began to suspect that what Dawson really needed was a sense of purpose. In 2003, he handed her one of his in-progress journal articles and asked her to copy-edit the grammar. So Dawson started reading. “I criticized his science almost immediately,” she says.

Encouraged by Dawson's interest, Mottron sent her other papers. She responded with written critiques of his work. Then one day in early 2003, she called with a question. “I asked: ‘How did they con-

trol for attention in that fMRI face study?’ That caught his attention.” Dawson had flagged an error that Mottron says most postdocs would have missed. He was impressed, and over the next few months he sought Dawson's input on other technical questions. Eventually, he invited her to collaborate with his research group, despite the fact that her only academic credential was a high school diploma.

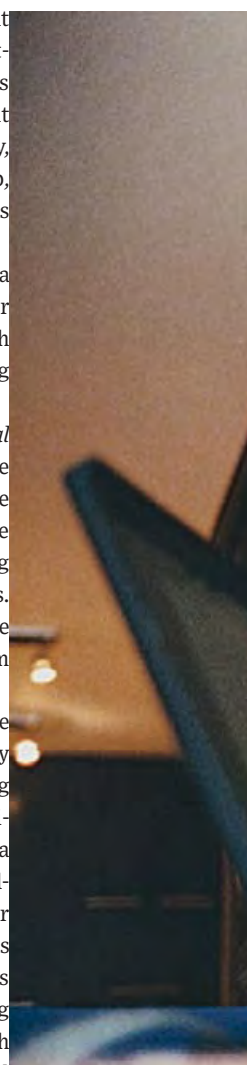
Dawson has an incredible memory, but she's not a savant. What makes her unique, Mottron says, is her gift for scientific analysis—the way she can sniff through methodologies and statistical manipulation, hunting down tiny errors and weak links in logic.

Last summer, the peer-reviewed journal *Psychological Science* published a study titled “The Level and Nature of Autistic Intelligence.” The lead author was Michelle Dawson. The paper argues that autistic smarts have been underestimated because the tools for assessing intelligence depend on techniques ill-suited to autistics. The researchers administered two different intelligence tests to 51 children and adults diagnosed with autism and to 43 non-autistic children and adults.

The first test, known as the Wechsler Intelligence Scale, has helped solidify the notion of peaks of ability amid otherwise pervasive mental retardation among autistics. The other test is Raven's Progressive Matrices, which requires neither a race against the clock nor a proctor breathing down your neck. The Raven is considered as reliable as the Wechsler, but the Wechsler is far more commonly used. Perhaps that's because it requires less effort for the average test taker. Raven measures abstract reasoning—“effortful” operations like spotting patterns or solving geometric puzzles. In contrast, much of the Wechsler assesses crystallized skills like acquired vocabulary, making correct change, or knowing that milk goes in the fridge and cereal in the cupboard—learned information that most people intuit or recall almost automatically.

What the researchers found was that while non-autistic subjects scored just about the same—a little above average—on both tests, the autistic group scored much better on the Raven. Two individuals' scores swung from the mentally retarded range to the 94th percentile. More significantly, the subset of autistic children in the study scored roughly 30 percentile points higher on the Raven than they did on the more language-dependent Wechsler, pulling all but a couple of them out of the range for mental retardation.

A number of scientists shrugged off the results—of course autistics would do better on nonverbal tests. But Dawson and her coauthors saw something more. The “peaks of ability” on the Wechsler correlated strongly with the average scores on the Raven. The finding suggests the Wechsler scores give only a glimpse of the autistics' intelligence, whereas the Raven—the gold standard of



intelligence tests that presume people who can't pick up a pen or tell you the answer DON'T KNOW THE ANSWER."



Michelle Dawson, right, is autistic. She's also a researcher in the lab of Laurent Mottron (left), a psychiatrist who specializes in autism.

fluid intelligence testing—reveals the true, or at least truer, level of general intelligence.

Yet to a remarkable degree, scientists conducting cognitive evaluations continue to use tests which presume that people who can't communicate the answer don't know the answer. The question is: Why? Greg Allen, an assistant professor of psychiatry at University of Texas Southwestern Medical Center, says that although most researchers know the Wechsler doesn't provide a good assessment of people with autism, there's pressure to use the test anyway. "Say you're submitting a grant to study autistic people by comparing them to a control group," he says. "The first question that comes up is: Did you control for IQ? Matching people on IQ is meant to clean up the methodology, but I think it can also end up damaging the study."

And that hurts autistic people, Dawson says. She makes a com-

parison with blindness. Of course blind people have a disability and need special accommodation. But you wouldn't give a blind person a test heavily dependent on vision and interpret their poor score as an accurate measure of intelligence. Mottron is unequivocal: Because of recent research, especially the Raven paper, it's clearer than ever that so-called low-functioning people like Amanda Baggs are more intelligent than once presumed.

The Dawson paper was hardly conclusive, but it generated buzz among scientists and the media. Mottron's team is now collaborating with Massachusetts General Hospital's Zeffiro, a neuroimaging expert, to dig deeper. Zeffiro and company are looking for variable types of mental processing *without* asking, what's wrong with this brain? Their first study compares fMRI results from autistic and control subjects whose brains were imaged while they performed the Raven test. The group is currently crunching numbers for publication, and the study looks both perplex-

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## I'm Autistic

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ing and promising.

Surprisingly, they didn't find any variability in which parts of the brain lit up when subjects performed the tasks. "We thought we'd see different patterns of activation," Zeffiro says, "but it looks like the similarities outweigh the dissimilarities." When they examined participants' Raven scores together with response times, however, they noticed something odd. The two groups had the same error rates, but as an aggregate, the autistics completed the tasks 40 percent faster than the non-autistics. "They spent less time coming up with the same number of right answers. The only explanation we can see right now," Zeffiro says, is that autistic brains working on this set of tasks "seem to be engaged at a higher level of efficiency." That may have to do with greater connectivity within an area or areas of the brain. He and other researchers are already exploring this hypothesis using diffusion tensor imaging, which measures the density of brain wiring.

But critics of the difference model reject the whole idea that autism is merely another example of neuro-diversity. After all, being able to plan your meals for the week or ask for directions bespeak important forms of intelligence. "If you pretend the areas that are troubled aren't there, you miss important aspects of the person," says Fred Volkmar, director of Yale's Child Study Center.

In the vast majority of journal articles, autism is referred to as a disorder, and the majority of neuro-psychiatric experts will tell you that the description fits—something is wrong with the autistic brain. UCSF's Merzenich, who agrees that conventional intelligence-testing tools are misleading, still doesn't think the difference model makes sense. Many autistics are probably smarter than we think, he says. But there's little question that more severe autism is characterized by what Merzenich terms

"grossly abnormal" brain development that can lead to a "catastrophic end state." Denying this reality, he says, is misguided. Yale's Volkmar likens it to telling a physically disabled person: "You don't need a wheelchair. Walk!"

Meanwhile parents, educators, and autism advocates worry that focusing on the latent abilities and intelligence of autistic people may eventually lead to cuts in funding both for research into a cure and services provided by government. As one mother of an autistic boy told me, "There's no question that my son needs treatment and a cure."

**Back in Burlington,** Baggs is cueing up another YouTube clip. She angles her computer screen so I can see it. Set to the soundtrack of Queen's "Under Pressure," it's a montage of close-up videos showing behaviors like pen clicking, thumb twiddling, and finger tapping. The message: Why are some stress-related behaviors socially permissible, while others—like the rocking bodies and flapping arms commonly associated with autism—are not? Hit count for the video at last check: 80,000 and climbing.

Should autism be treated? Yes, says Baggs, it should be treated with respect. "People aren't interested in us functioning with the brains we have," she says, because autism is considered to be outside the range of normal variability. "I don't fit the stereotype of autism. But who does?" she asks, hammering especially hard on the keyboard. "The definition of autism is so fluid and changing every few years." What's exciting, she says, is that Mottron and other scientists have "found universal strengths where others usually look for universal deficits." Neuro-cognitive science, she says, is finally catching up to what she and many other adults with autism have been saying all along.

Baggs is working on some new videos. One project is tentatively titled "Am I a Person Yet?" She'll explore communication, empathy, self-reflection—core elements of the human experience that have at times been used to define personhood itself. And at various points during the clip, she'll ask: "Am I a person yet?" It's a provocative idea, and you might find yourself thinking: She has a point. ■

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**DAVID WOLMAN** (david@david-wolman.com) wrote about a terrorist attack response drill in issue 16.02.