



Living with autism in a world made for others

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- Amanda Baggs, 26, is part of new generation of adults with autism
- Baggs communicates using a computer or a voice synthesizer
- 600,000 adults have autism in the U.S., according to the Autism Society of America
- No cure for autism; precise causes unknown

By A. Chris Gajilan
CNN

(CNN) -- When I walk into her apartment, Amanda Baggs makes no eye contact. She doesn't come to the door or raise her hand to greet visitors. In fact, I'm having a hard time discerning whether she even knows I'm there. I say hello and introduce myself, but she remains silent, sitting at her desk, staring out the window, rocking slightly back and forth.

Amanda Baggs is a 26-year-old woman with autism. I've been corresponding with her for weeks via e-mail. I've read her Web site, and from her I've learned a great deal about living with autism.

[A video she posted recently](#) on the Internet describes how she experiences the world. "My language is not about designing words or even visual symbols for people to interpret," she says in the video. "It is about being in a constant conversation with every aspect of my environment."

Admittedly, it's hard to recognize her in real life, after meeting her online persona first. ([Read Dr. Sanjay Gupta's thoughts after meeting Amanda Baggs.](#))

I awkwardly carry on a one-sided conversation, until she grunts. My attention shifts to her computer slowly booting up. She clicks on a program. A keyboard diagram fills the screen. She begins to type at a staccato pace. We begin a conversation. I talk. She types. ([Watch Amanda communicate in her own way](#))

This is the Amanda I've come to know over the past few weeks. She's highly intelligent, well read and has a great sense of humor. She never makes eye contact, but there is no doubt she is interacting with me.

Amanda is part of a new generation of adults with autism. The Autism Society of America estimates that 600,000 adults are living with autism in the United States. That number will most likely skyrocket, given the CDC's recognition of an increase in the numbers of children with autism. The newest numbers suggest that one in every 150 children has autism.

"The field as a whole has really neglected adults with autism," says Dr. Eric Hollander, psychiatrist and head of the Seaver and New York Autism Center of Excellence.

Adults with autism live normal life spans and may require long-term medication, therapy and residential placement. Hollander says the average cost of caring for an individual with autism over a lifetime can be several million dollars.

Autism treatment and research are undeniably centered on children. The goals are early diagnosis and intervention. They're aimed at reducing disruptive behaviors and eventually mainstreaming children with autism into school and society.

At its core, autism is a developmental disorder of communication. There is no cure. No one knows the precise causes, but recent science points towards a genetic component with a possible environmental trigger.

Amanda Baggs has severe autism. She didn't cry when she was born. She had to be taught how to nurse. As a little girl, she rocked her head back and forth but could speak. As she grew, she would go longer and longer without speaking, until her spoken language disappeared altogether. ([Read Amanda's post to the AC 360 blog on CNN.com.](#))

She slowly learned how to type. Now, she relies on her computer or a voice synthesizer linked to a keyboard to interact with people. According to Hollander, "You might think that these individuals are mentally retarded or have no verbal skills, but in fact, they're not mentally retarded. They really understand what is going on and if they utilize a communication device, they can really communicate what they are thinking and feeling."

For Amanda, it takes a great deal of energy to think in words. It is not her natural state of mind. "It's like being bilingual," she types. "A lot of the way I naturally communicate is just through direct response to what is around me in a very physical sort of way. It's dealing with patterns and colors rather than with symbolic words." ([Watch why "normal" communication isn't for Amanda](#))

The Internet has allowed Amanda to communicate to the whole world. While standard body language and facial expressions are lost on many with autism, she says many non-verbal people with autism have the ability to communicate with one another through autistic body cues.

Thirty or 40 years ago, life would have been different and much harder for Amanda, says Morton Ann Gernsbacher, a cognitive psychologist who specializes in autism at the University of Wisconsin-Madison. "The Internet is providing for individuals with autism, what sign language did for the deaf," she says. "It allows them to interact with the world and other like-minded individuals on their own terms." ([Ask Amanda your questions about autism.](#))

These days, Amanda Baggs lives on her own terms. With the help of an agency, she moved from California to Vermont about a year and a half ago to be closer to a friend.

And what does Amanda think is the hardest thing about living with autism? "Having to navigate a world that is, on all levels, is built for the abilities and deficits of people who are not built remotely like me."

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