

**DEEP DIVE, FEATURES**

# Suicidal thoughts alarmingly common in people with autism

BY SARAH DEWEERDT

31 JULY 2014



*Illustration by Julia Yellow*

*Julia Yellow*

As a teenager, Bianca Marshack often flew into rages over seemingly minor problems — as when her mother, Kathy, didn't bring her favorite chicken dinner home from the grocery store. Her anger would quickly spiral out of control, and she would threaten to kill herself.

"I would try to just hold her, to calm her down and say, 'I'm here, I'm here for you,'" recalls **Kathy Marshack**, a Portland, Oregon-area psychologist.

Bianca had been diagnosed at age 13 with a high-functioning form of autism called **Asperger syndrome**, and as she got older her moods could be explosive. "Sometimes she would say, 'If you would just kill me, then we would both not have to suffer anymore,'" Kathy remembers.

Bianca's behavior reflects the striking paradox of emotional turmoil in autism, an aspect of the disorder that has received attention only in the past few years. Often, people with the disorder can seem emotionless, with a flat affect and little interest in talking about feelings — their own or anyone else's. But they may also have outbursts in which they make dramatic, shocking threats to end their lives.

Experienced clinicians have long had a sense that people with autism are at increased risk of 'suicidality,' which encompasses thoughts, plans and attempts to kill oneself. Their suspicions have been borne out in recent years: Several large studies of adolescents and adults with autism reveal that bleak moods and suicidal despair are alarmingly common, particularly among those on the milder end of the spectrum with so-called high-functioning autism or Asperger syndrome.

At the same time, this suicidality may be difficult to recognize, because people with autism don't talk about their emotions in typical ways — for example, they may report feeling suicidal without describing themselves as depressed.

In the most recent study, published in June in *The Lancet Psychiatry*, two-thirds of a group of adults diagnosed with Asperger syndrome said they had thought about committing suicide at some point, and 35 percent had made specific plans or actually made an attempt<sup>1</sup>.

"These are individuals who have been struggling all their lives to fit in," says study leader **Simon Baron-Cohen**, professor of developmental psychopathology at the University of Cambridge in the U.K. "Along the way, they have really been suffering."

In fact, researchers say, some of the cognitive patterns seen in people with autism, such as the **tendency to perseverate** or **get stuck on a particular line of thought**, may make these individuals particularly vulnerable to suicidality. With this new evidence, they are starting to look for ways to identify suicidality and prevent it in this population.

“This is a community in distress,” says **Katherine Gotham**, assistant professor of psychiatry at Vanderbilt University in Nashville, Tennessee, who studies depression in autism. “This is something we need to know more about and do something about, and the faster the better.”

## Hidden epidemic:

For a long time, suicide was largely ignored by autism researchers. “When I got started taking care of people with autism, there was this belief that it’s not possible for them to have depression,” says **Janet Lainhart**, professor of psychiatry at the University of Wisconsin in Madison. People with autism were thought to have little experience of emotion, let alone of suicidal despair.

Through the 1990s and 2000s, even as knowledge and awareness of autism rapidly accelerated, few rigorous studies investigated the topic<sup>2</sup>. One of the earliest, in 2007, involved just a few people but offered a strong suggestion that persistent, serious thoughts of suicide are common. In that study, ten adolescents with Asperger syndrome answered a detailed questionnaire about how frequently they had had various suicidal thoughts over the previous month. Half scored in a range that indicates high risk for suicide<sup>3</sup>.

Although Asperger syndrome is **no longer an official diagnosis** in the *Diagnostic and Statistical Manual of Mental Disorders*, the term is still in use in the U.K. and elsewhere, and many individuals still identify with it.

In the past couple of years, larger studies have confirmed that suicidality is common among young people with autism. Last year, researchers reported that among 791 children with autism younger than age 16, **14 percent had either talked about or attempted suicide**, compared with just 0.5 percent of children without autism<sup>4</sup>. Another study of 102 children aged 7 to 16 with anxiety and high-functioning autism found that 11 percent had suicidal thoughts and behaviors<sup>5</sup>.

Teenagers are already at a higher risk of suicide because of the emotional and social turmoil of adolescence. Having autism intensifies these difficulties, says **Oren Shtayermman**, associate professor in the School of Health Professions at the New York Institute of Technology, who conducted the 2007 study. “As they become adolescents, they become more and more ostracized from their peer groups,” he says. “They become more and more isolated from society.”

Age may not offer any relief from this sense of isolation. An **unpublished analysis of medical records** of more than 2,000 California adults with autism found that 1.8 percent of these individuals attempted suicide between 2008 and 2012, compared with 0.3 percent of controls.

Rehan Siddiqui became severely depressed in early 2001, during his second semester of college. “I had no friends, really. I went to class, I attended lectures, but had no one to hang out with.” During that period, he sometimes thought about ending his life, but was too deeply depressed to take any action. “I said I wish I would die, I wish I would die in a car crash, stuff like that,” he recalls. When he was diagnosed with Asperger syndrome nearly two years later, it came as a great relief, he says: “Finally there was a reason for why I’m so different.”

“These are individuals who have been struggling all their lives to fit in. Along the way, they have really been suffering.”

Some researchers say people like Siddiqui may be even more vulnerable to suicidality than those diagnosed as children, having spent years to decades without an explanation for their struggles — and without access to help. The 374 participants in Baron-Cohen’s study, for example, were diagnosed at an average age of 31. They were nine times more likely than people in the general population to experience suicidal thoughts.

The adults with autism in the California study were more than five times more likely than controls to attempt suicide. “I think this is the tip of the iceberg in terms of the bigger picture of suicidal ideation,” says **Lisa Croen**, director of the Autism Research Program at Kaiser Permanente, a nonprofit health care system based in California.

For many people with the disorder, the longing for social and romantic relationships, independence and meaningful work is intense, but there are few programs **to help them fulfill these basic human desires**.

Siddiqui says his hope is “to live a nice, independent life.” He lives with a roommate and is excited that he recently got a car, because it will help him stay more socially engaged. But bouts of depression — winter is especially difficult — have sometimes prevented him from working. “I’ve had my ups and downs,” he says. “Ideally, I would love to have a job where I can support myself without any government support.”

## Depression’s new face:

Among the general population, most people who become suicidal are depressed. That’s true among people with autism too<sup>4</sup>. And because people with autism **have high rates of depression**, it’s not surprising that they are frequently suicidal.

Still, traditional screens for depression may miss the emotional experience of people with autism. In Baron-Cohen’s study, suicidality was far more common than depression as it is usually diagnosed. Although 66 percent of the participants reported having suicidal thoughts, less than half as many reported feelings of depression.



That's not because they don't have those feelings, however. "They may not be able to access or have the vocabulary to describe their emotional state," says Baron-Cohen. This condition, called alexithymia, is common in people with autism.

Yet if clinicians listen closely, they may hear clues — albeit not the usual ones. People with autism may be unlikely to describe themselves as depressed, but "they will explain their emotional pain in idiosyncratic ways," says Lainhart.

One clinician recalls an individual with autism who was so deeply sad and hopeless that he described himself as "now darkness." Another said she constantly thought that the time had come for her leave this planet, in search of another galaxy where she would fit in better and find a friend.

The way people with autism think may itself make them more vulnerable to suicidality. For example, they often don't think to reach out to others when they are upset: Asking for help is, after all, a social skill.

They also tend to have rigid, inflexible thinking, so once suicide enters their mind, it may stay there. Gotham and her colleagues have found that patterns of **repetitive thought contribute to depression** in people with autism. "I think that there could be something similar going on with suicidality," she says.

People with autism often struggle to imagine the thoughts and feelings of others, including their own future selves. As a result, they may have trouble believing they will ever feel better. They can also easily become overwhelmed by the small but complex problems of everyday life and respond with extreme thoughts or statements.

In the study of children with anxiety and high-functioning autism, researchers found that the children sometimes made suicidal threats for attention or to escape from an unpleasant situation. "Often it was a reaction to some limit being set or placed on the child," says study leader **Eric Storch**, professor of pediatrics, psychology and psychiatry at the University of South Florida in Tampa. For example, a parent might announce that it's time to stop playing video games, and a child might throw a tantrum, lose control and say that he is going to kill himself.

Regardless of the intent, parents and clinicians should take threats of suicide from people with autism seriously. "It's their best attempt to raise a red flag saying that they need help," says Lainhart.

Storch and his colleagues are developing a program for suicidal teens with autism based on a similar one for those with Tourette syndrome. The next step for Baron-Cohen's group is simple but unusual: The researchers plan to ask people from the Asperger syndrome clinic what would help them.

“We just have to be a little bit cautious not to jump to solutions that are off-the-shelf,” Baron-Cohen says. For example, telephone crisis lines are often recommended for suicidally depressed people — but because of their social deficits, people with autism may be unlikely to call.

Since her daughter’s diagnosis, Kathy Marshack has oriented her psychotherapy practice to help families who have a child or parent on the autism spectrum.

“At the time, it was frightening to me that Bianca was suicidal,” Marshack says. But looking back, she says, her daughter probably lacked the empathy to recognize the effect her pleas about wanting to die would have on her mother. “She was in such pain,” Marshack says. “She was trying to say, ‘I feel helpless.’”

## References:

- 1: Cassidy S. *et al. The Lancet Psychiatry* **1**, 142-147 (2014) [Abstract](#)
- 2:Hannon G. and E.P. Taylor *Clin. Psychol. Rev.* **33**, 1197-1204 (2013) [PubMed](#)
- 3: Shtayermman O. *Issues Compr. Pediatr. Nurs.* **30**, 87-107 (2007) [PubMed](#)
- 4: Mayes S.D. *et al. Res. Autism Spect. Disord.* **7**, 109-119 (2013) [Abstract](#)
- 5: Storch E.A. *et al. J. Autism Dev. Disord.* **43**, 2450-2459 (2013) [PubMed](#)

## REFERENCES:

1. Cassidy S. *et al. The Lancet Psychiatry* **1**, 142-147 (2014) [Abstract](#)
2. Hannon G. and E.P. Taylor *Clin. Psychol. Rev.* **33**, 1197-1204 (2013) [PubMed](#)
3. Shtayermman O. *Issues Compr. Pediatr. Nurs.* **30**, 87-107 (2007) [PubMed](#)
4. Mayes S.D. *et al. Res. Autism Spect. Disord.* **7**, 109-119 (2013) [Abstract](#)
5. Storch E.A. *et al. J. Autism Dev. Disord.* **43**, 2450-2459 (2013) [PubMed](#)