

VIEWPOINT

Call for help: We need to address suicide risk in autistic women

BY SARA LUTERMAN

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Listen to this story:

I don't remember much about the day I tried to kill myself.

I remember sitting numbly in a beige office as I was let go from my first job after less than two weeks. No one would tell me what I had done wrong. I remember walking along the National Mall in Washington, D.C., to the closest subway station. The air was cold and full of sunshine. I rode the train all the way back to the suburbs. I got off the train. I remember the doors closing. I remember feeling the deafening rattle of the train as it left.

I thought about how easy it would be for me to just fall in front of the next train. Peak hours were starting soon, so I wouldn't have to wait long. I stood with my toes at the edge of the platform, ready to lean forward. Ready to just let go.

"Whoa, watch out! You almost fell there."

A man caught me. I didn't die. I started crying and sat down on the ground.

"I need to go to the hospital," I said. That was what my psychiatrist had told me to do if I ever actually thought I might kill myself. He asked me which hospital I meant.

"I need to go to the hospital," I repeated. My face got hot and red as I began to sob. I slammed my fist into my head a few times, then I started on my leg. "I need to go to the hospital."

I got into the man's car and he drove me to the nearest hospital.

I am an autistic adult. Many of my friends are also autistic adults. In the past few years, some have attempted suicide. Some have died.

For a few years now, researchers have known that **suicide is a major issue** for autistic people. The first population study on **autism and suicide**, published in 2015, shows it is the second biggest killer of autistic adults without intellectual disability, after heart disease.

The study included more than 27,000 autistic people and 2.7 million controls in Sweden. It revealed that the suicide rate among autistic individuals is nearly eight times that among non-autistic people.

It also exposed a truth that echoes my experience at the train station: Women with autism are more than 13 times as likely to die by suicide as those without autism.

An analysis of data over 20 years, published in January, is the largest **population study of autism and suicide** to date. It confirms the high rates of suicide among autistic women¹.

These and a few smaller studies paint a clear picture: Suicide is unusually prevalent among autistic adults — and autistic women are at especially high risk.

I'm grateful that this topic is finally receiving more attention, but it is hardly enough. There are so many unanswered questions — including the all-important: *Why?*

Scant support:

Suicide has been the subject of a special-interest group for researchers at the **International Society for Autism Research** (INSAR) annual meeting for the past three years. I attended the session last year. Sitting in a room full of researchers whose work directly addresses the needs of autistic adults is humbling, because few researchers care to do so. But I was still shocked by how small the room was, and by how few researchers were present.

Autism research funding priorities are disproportionately focused on genetics and the abolition of autism's 'core traits,' such as social difficulties and **repetitive behaviors**.

Millions of dollars go to genetically altered zebrafish and rats that groom too much, but hardly any to finding out why so many autistic adults attempt suicide. Until several years ago, there was no money at all.

It is not only in the United States that funding priorities for autism center on biological mechanisms and core traits in children. At INSAR, as I drank my morning coffee, I had the astounding luck to sit next to **Tatja Hirvikoski**, associate professor in the Division of Neuropsychiatry at the Karolinska

Institutet in Sweden. Hirvikoski led the 2015 population study. As we chatted, I was shocked to learn that she had not received a grant for her groundbreaking research. (**Anne Kirby** of the University of Utah, who led the January study, did have a grant for her work.)

Unseen, unhelped, ignored:

Kirby and her colleagues found that autistic people without intellectual disabilities are significantly more likely than people in the general population to attempt suicide. But the enormity of the dataset — nearly 17,000 people, including more than 4,000 women — enabled them to draw more conclusions about gender and suicide than others have.

For instance, autistic women are three times as likely as non-autistic women to die from suicide.

I met Kirby at INSAR, too. A few months later, she reached out to me to discuss where to take her research next. She told me she remembered me and my story, and she remembered how grateful I had been to be in a room full of people who cared enough to study something unglamorous and underfunded, but utterly necessary. I look forward to collaborating with her.

One of the questions I would like to help investigate is why autistic women are at risk for suicide. Some clues: Women are diagnosed later than autistic men are. And researchers have pointed to **structural differences** in the brains of autistic men and women, but the precise impact of those differences on behavior is unclear.

What is clear is that many **autistic women go unseen**, unhelped and ignored — all of which puts us at high risk for suicide. I was one of those overlooked women.

Although an autism diagnosis as an adult has improved my life and I am happy, I think about how my life and my mental health could have been different if I had known at an earlier age that I was autistic. If I had had better psychological support, would I have kept that job? Would I have gone somewhere else that day instead of considering how easy it would have been on the train platform to just take that one step forward?

Missed potential:

Because of the lack of research on suicide among autistic women, I can only speculate about the factors that have kept me alive. I am lucky to have a good support system. I have friends who visited me in the hospital and helped me get back on my feet. I try to be a good friend and visit others in return. And I have a strong sense of my rights as a consumer. If I don't like a psychiatrist or a therapist, I am proactive about finding someone new. I am also proactive about finding medications that work for me.

I also take evidence-based steps around what is called '**means reduction**,' giving myself fewer

opportunities to attempt suicide. One fascinating 1976 study showed that after the United Kingdom switched from ovens fueled by coal gas, which is high in carbon monoxide, to natural gas in homes, suicides dropped by one-third². I don't own a gun, and I dispose of medications once I no longer need them. These are choices I make because I want to stay alive.

It has been a number of years since that moment on the platform. But I do not want pity. What I want is a change in funding priorities. Since my suicide attempt, I have seen geysers erupt at Yellowstone National Park. I've tasted fresh herring with chopped pickle and onion at a street market in Amsterdam. I have rubbed elbows with C-Suite executives at Microsoft's **Autism at Work Summit**. And I have met the person with whom I hope to spend the rest of my life.

I would have missed all of that if I had died. Sometimes, when I can't sleep, I think about all of the missed potential. I think about people who were just like me, but who did step in front of the oncoming train.

The question I want the answer to most of all is this: How can we stop it?

Sara Luterman is a freelance writer and founder of NOS Magazine, the first online news and culture site by and for the neurodiversity community.

*If you or someone you know is having suicidal thoughts, help is available. **Click here** for a worldwide directory of resources and hotlines that you can call for support.*

REFERENCES:

1. Kirby A.V. *et al.* *Autism Res.* Epub ahead of print (2019) **PubMed**
2. Kreitman N. *Br. J. Prev. Soc. Med.* **30**, 86-93 (1976) **PubMed**