

Creative Works

On Speaking and Not Speaking: Autism, Friendship, Interdependency

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This collection of autobiographical fragments explores the subject of autistic voice. Juxtaposing moments when autistic communication is recognized and understood with moments in which it isn't, this work of creative nonfiction examines ideological tensions between independence and interdependency, the potential lines (or lack of lines) separating friendship and support, and some of the inevitable problems that are created when one person speaks for another. The piece also explores the dangers that may arise when social systems and authority figures fail to recognize autistic voices.

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1

I am 12 years old, riding the school bus. "Where are you from?" the girl sitting next to me asks. When I tell her that "I have lived here in town all of my life," she is amazed. Although we have been in the same class all year, she has never heard me speak before. She had assumed that I could not speak English.

2

I am 16 years old, having a meltdown. All I know is that I can't communicate, that I have become chaos and entropy. I lie on the floor of my bedroom and scream for hours. I cover my ears so that I won't hear the sound of my own screaming.

3

I am 22 years old, working on a Ph.D. at the University of Georgia. I can't navigate the crowded, noisy streets downtown by myself, but my friends often take me. "Do you want sour cream?" The restaurant is even more crowded and noisy than the perfectly unnavigable street, the line behind me steadily building. My friend, Jess, chews at her bottom lip, uncertain of what to do. The majority of the time, I speak just fine. Except when I don't. So my friend is having a dilemma. Should she order for me? Should she give me more time? She would never dare to speak for another—to trample on someone else's subjectivity. But the problem we are having is practical as well as philosophical: I do want sour cream, even if I can't ask for it. I wish Jess would speak for me. The crowd at my back builds precariously. The silence lengthens.

4

I am 27 years old, a professor of English on my way to a professional conference. The senior shouting officer of the TSA (my friend Lisa says that the TSA in Atlanta have officers employed explicitly for shouting) is doing his best work at maximum volume. He can't tell that I'm autistic, and he can't figure out why yelling "move to the left" isn't helping me move to the left. Actually, I'm not moving at all: I'm standing helplessly still in a sea of moving people. I can't understand why this man is yelling at me nor understand what he is yelling about. Lisa, hesitant to touch me, is also trying to get me to move to the left. But my body isn't doing what it's told.

"You can't separate us." Lisa is trying to stay calm in the chaos that is airport security. "I'm her assistant. You won't be able to communicate with her without me."

"What number are you?" she asks later as we get on the plane. No response. Long pause. "What number are you?" she types on her phone. The ability to type, unlike the fleeting ability to speak, rarely leaves me: I type "9." Lisa breathes deeply and calmly, while I sit beside her, my face in my hands. On our 1-10 scale, a 10 is a full-blown meltdown. You can't have a meltdown on a plane, I think to myself. You can't have a meltdown on a plane. THERE IS NO PLACE TO HAVE A MELTDOWN ON A PLANE. "Security thought you were deaf," Lisa says later, when it has passed.

5

I am pregnant, six months along. "It won't hurt you," the doctor says in an attempt to be reassuring. I can't say anything in response. I have yet to realize that the most complicated part of my very complicated pregnancy will be my inability to communicate with my doctors. I want to say, "I feel like I'm dying."

Later, the doctors discover that I am, in fact, dying. So is the baby. They need to do an emergency C-section. I can't answer basic questions—can't make any noise at all. When they cut me open, my husband says anxiously, "Shouldn't you check to see if she can feel that?" My whole body trembles. "If she could feel that, she would be screaming right now," the doctor says confidently.

6

I am never singular, never alone. This duality confuses people. Who is this person with her? What is this person's role? At the Comparative Drama Conference, my friend Steph is mistaken for my lover. ("You make an adorable couple," a conference-goer says to her during my presentation, "You must be so proud—she's so articulate!") At the Modern Language Association, Lisa is mistaken for my graduate student. When Lisa explains that she is my support person, the chair of my disability studies panel asks, "So you are helping her travel? How does that work?"

At the Society for Disability Studies conference, people aren't quite sure how to work conversationally with my support person. I am glad that people are talking to me, but I am

sorry that they are ignoring my friend. Even in disability circles, independence remains an alluring ideology. We want to regard independence as the end goal—the sign of adulthood, the mark of arrival. We want to believe that independence is possible for everyone. I recognize the dilemma: to engage my support person in conversation may seem to overlook me in my autistic silence, may seem in some way to fail to acknowledge my disabled humanity. But Steph is a brilliant gal. Like all of my friends who help me travel, she doesn't get paid for her work.

My autism specialist is surprised to hear that my friends travel with me to conferences, that they have made my career possible. She is surprised to find that they take me to doctor's appointments and help me to get my hair cut. She fails to recognize that our relationships are complex and symbiotic, that I also give. This makes Lisa and Steph angry. "You have good friends," Lisa says, "because you are a good friend." My autism specialist seems to assume that I am a burden rather than a friend. Sometimes I worry that she is right.

7

I am 31 years old, having a meltdown. I lie on the bathroom floor and scream. My husband lies down on the floor beside me, just far enough away so that I know he isn't trying to touch me. He lies there without speaking, a silent solidarity in the lines of his body. He waits. He smiles. He is patient. In our 11 years of marriage, it is the most romantic thing that he has ever done for me.

8

I am 33 years old, and I need to have surgery. The hospital cannot decide whether to treat me as a child or as an adult. Angry conversations are held in front of me about my legal status. "She is an adult, and she can speak," the ultrasound technician says, "Legally, she *must* speak for herself." But I can't speak for myself at the moment, so I cover my ears with my hands and scream.

The hospital says that they cannot allow a support person in the recovery room. "If she has a meltdown, I can't guarantee that they won't use restraints," the hospital administrator says. In the weeks leading up to the surgery, I lie awake in bed at night and imagine the restraints. I know that I may not be able to communicate with the nurses and that they may not look closely at my medical records. "We should write the word AUTISM on your arm with a Sharpie," my friend Allison says. I imagine inscribing my body with my disability label as the ultimate act of both acceptance and defiance.

The doctors give me so many anxiety drugs that I don't remember the surgery at all. In the weeks that follow, I'm so grateful that I can't remember. But my friend Alice is angry. "There shouldn't be things you don't want to remember," she says. I understand Alice but do not agree with her. Alice imagines a world in which the medical system accommodates and cares

for people like me. Such a world is a theoretical possibility, I know, but it isn't the one I have lived in. For my part, I am glad that the drugs have erased the sound of my screaming.

9

“What kind of ice cream do you want?” The man behind the counter can tell that there is something “wrong” with me. My friend Ann, whom I met on the floor during circle time in Kindergarten, is sizing me up with her knowing eye: after twenty-eight years of friendship, she knows intimately what an incipient meltdown looks like. It is too crowded in here. Much too crowded. “She wants strawberry,” Ann says with false confidence. She slams the palm of her hand down on the wooden bar in front of us. “Definitely the strawberry.” And I am glad to have the strawberry ice cream, glad that Ann hustles me into a quiet seat in a hurry, so very grateful to have had Ann to speak for me all of these years. It is dangerous and beautiful and bittersweet, this speaking for me. After all, if someone doesn't speak for you, you don't get any ice cream at all—but I wish I could tell her that I wanted cookies and cream.

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