

## Rainbow Rant: Remembering Susan Nussbaum

*The disabled writer, actress and activist died on April 28 after a lifetime of fearless truth-telling, radical pleasure-seeking, and brave action*

Joy Ellison

I've lost a hero and role model. Susan Nussbaum was a disabled writer, actress, activist and the author of *Good Kings Bad Kings*, one of my favorite books. She showed me how to write fiction that is both fiercely political and beautifully personal. More importantly, she showed me how to take pride and pleasure in my identity as a disabled person.

Susan [died on April 28](#) surrounded by friends and family in her Chicago apartment after a life of fearless truth-telling, radical pleasure-seeking and brave action. She was 68 years old.

It's not your fault if you have never heard of Susan. In a more just world, you would have read her novel *Good Kings Bad Kings* in your high school English class or noticed a review of one of her plays in the newspaper. If we valued the lives of disabled people, you would have seen a picture of her at a disability rights protest in the 1970s in a history book. But we don't and you probably haven't.

The lives of disabled people are hidden from view and shaped by a web of interlocking systems of injustice. Susan used her pen to reveal this reality and her body and heart to seize the power denied to disabled people. She is one of the most important writers of our century, to me at least.

The first time I met Susan, I got her stuck in an elevator.

In 2014, I organized Susan's visit to DePaul University. As part of my preparations, I checked all of the spaces where she would speak to ensure she could access them in her wheelchair. The facility manager seemed to think that I was rather paranoid, but I knew that the university was often less accessible than it appeared, and I wanted Susan's visit to go smoothly.

At first, it did. Susan rolled through building after building and spoke movingly about her novel and her work for disability justice. She answered my students' questions graciously. The visit was a rousing success until the evening talk, which was held in a fancy building where the pictures of dozens of priests who served as university presidents scowled down at us from the walls. Susan asked me to direct her to the bathroom. I said it was downstairs and pointed her toward a tiny elevator. Susan wheeled her way into it and pressed the down button. The elevator began its descent, but halfway between floors, it stopped. Susan was stuck.

I don't remember how we freed Susan from that abominable elevator, but I'll never forget what she said to me at the end of the evening, when she needed to go to the bathroom again. When I explained that the nearest bathroom that could be accessed without risking confinement was a few blocks away, Susan balked.

"I'll just pee outside," she told me, with an air that made it clear she had plenty of practice urinating in public. "What are they going to do to me?"

Nothing could more clearly show two of Susan's profound talents: her knack for revealing the absurdity and horror of ableism and her rebellious insistence on meeting her basic needs with dignity and humor.

To Susan's credit, when we ran into each other a couple of years later at a protest rally, she greeted me like a friend. It's telling that I can't remember the reason for the rally. It may have been a Black lives matter protest, but it could just as easily been in support of the Chicago Teacher's Union. Susan would have shown up to either.

Susan became a wheelchair user at age 24 when she was hit by a car. At the time, she was in acting school, but all the theaters in Chicago were inaccessible. She reinvented herself as a playwright, changing the world that refused to allow her in.

Susan joined the disability rights movement in the late 1970s, when it was barely organized in the Midwest. There, she found community within a group she described as "surprisingly militant." With her new comrades, she worked to dismantle the systemic barriers that infantilized, criminalized and discriminated against disabled people. "My transformation from shamed victim to furiously rebellious crip," she wrote, "was the foundation of my new identity. Still is."

For Susan, writing became another way to wage political struggle. She wrote many plays and her novel *Good Kings Bad Kings* won the 2008 Bellwether Prize for Socially Engaged Fiction. The book tells the story of a group of disabled teenagers who live in a nursing home. It's a dangerous place with arbitrary rules, populated mostly by disabled people of color and those who are poor. Most people don't know that this kind of institution exists, but through the first-person voices of seven characters, Susan deftly illustrates why so many disabled people are trying to escape places like it. *Good Kings Bad Kings* pulls no punches, but it is also filled with humor and hope, just like the lives of disabled people.

Susan might be best known for her writing, but she is probably best loved for her work with the Empowered FeFes, one of the first groups for disabled women. Focusing on sexual health, disability access and racial justice, the Empowered FeFes reflected Susan's passion for pleasure. The Empowered FeFes are still redefining feminism to make it serve

the needs of disabled women of color. They are just a few of the people whose lives have been touch by Susan and who carry out her legacy.

You can honor Susan, too. Read *Good Kings Bad Kings*. Remove access barriers wherever you find them. Create networks of care and protest. Flip off ableism. Piss in public when you have to. And do it all with love.