

# *Good Kings Bad Kings*

A Note from the Author

A Conversation with the Author

Questions for Discussion





## A Note from the Author

I used to wonder where all the writers who have used disabled characters so liberally in their work were doing their research. When I became a wheelchair-user in the late seventies, all I knew about being disabled I learned from reading books and watching movies, and that scared the shit out of me. Tiny Tim was long-suffering and angelic and was cured at the end. Quasimodo was a monster who loved in vain and was killed at the end, but it was for the best. Lenny was a child who killed anything soft, and George had to shoot him. It was a mercy killing. Ahab was a bitter amputee and didn't care how many died in his mad pursuit to avenge himself on a whale. Laura Wingfield had a limp, so no man would ever love her.

This imagery fresh in my mind, my own future seemed to hold little promise. I had been in acting school at the time I

was injured. As all of the theaters were now inaccessible to me, both behind the stage and in front, and the chances of any director in the world hiring me were remote, I decided I had no choice but to reinvent myself.

I joined the disability rights movement, barely organized in Chicago back then, and quickly came to realize that I was not alone. My surprisingly militant comrades and I addressed ourselves to the issues that were most pressing at the time—fighting and winning the right to wheelchair accessible public transportation, the remodeling of sidewalks, schools, stores, theaters, and the rest of the world, and protesting the systemic discrimination against us in every aspect of the bureaucracy we had become so dependent upon. My transformation from shamed victim to furiously rebellious cripple (we took back the word that had oppressed us and used it in our own proud new vocabulary of defiance) was the foundation of my new identity. Still is.

As the scope of our movement broadened, so did my view of what was possible. I became a writer. If the dominant culture was saturated with backward concepts of who we were, I would answer back with my own collection of disabled characters. None of those people writing books and movies that exploited their disabled characters as “symbols” were disabled themselves. And who were these glamorous stars dying to catch that juicy disabled role, to do their best imitations and take home their Oscar? They knew little if anything about the experiences of real disabled people. I *knew* the world, the jokes, the words, the underground details. I knew all three dimensions, not the tired

one dimension they put out there for the public to eat. I knew the struggles, the brutality of oppression, the love that held us together. I was the real thing, the authentic article. A genuine crip writer, writing about crips.

None of the characters I write about are particularly courageous or angelic or suicidal, bitter for their fate, ashamed to be alive, apt to kill anyone because they have an intellectual or psychiatric disability, or dreaming of being cured or even vaguely concerned with being cured.

I wrote plays. Having been an actress, that's how I saw and heard my characters. They were all produced, all relatively successful. All but one play. My last play and also my best play. I was sure I would break through the barriers with this one. Like African American writers who had to fight for their own authentic voices onstage—that would be me with disabled voices. I got a New York agent! But no matter how close I got, I couldn't get it produced, and I gave up writing. I think my heart was broken.

But eventually I decided to reinvent myself. Re-reinvent myself.

My book is about a bunch of disabled people who live in an institution for kids with disabilities. Some of the characters work there. Being trapped in one kind of institution or another is the fate of many of us. The characters in my book are dealing with a place that's not one of the worst, but abuse and neglect are rampant nonetheless. Some of them are sucked under by the riptide of repression, some of them bob to the surface against all odds, and maybe one or two find a way to fly away.



## A Conversation with the Author

Susan Nussbaum's debut novel, winner of the PEN/Bellwether Prize for Socially Engaged Fiction, is, as Rosellen Brown says, "a celebration of strength, dignity, and the cathartic pleasure of telling it like it is."

Set in a nursing home for young adults with disabilities, *Good Kings Bad Kings* mines the lives of seven characters: a diverse group of young people and their caregivers. Nussbaum, who is an award-winning playwright, masterfully channels the voices of her characters, including a disabled Hispanic teen trying to find her way after losing the grandmother who raised her, a wheelchair-bound woman who is seeking new love and new meaning in her life, and a young man who wants to enjoy living and loving independent of any institution. They may inhabit a world unfamiliar to many, but the core of who they are,

the heart of their joys and suffering, are intensely universal. Yes, this novel will make you ache, but in the very best way.

*Good Kings Bad Kings* is a marvel that does what the best fiction does. As Barbara Kingsolver, the founder of the PEN/Bellwether Prize, explains: “Fiction . . . creat[es] empathy in a reader’s heart for the theoretical stranger.” Thanks to Nussbaum, the characters of *Good Kings Bad Kings* are strangers no more.

Here, she is interviewed by Heidi Durrow, the *New York Times* bestselling author of *The Girl Who Fell from the Sky*, which received the 2008 PEN/Bellwether Prize for Socially Engaged Fiction.

**Heidi Durrow:** What was the inspiration for *Good Kings Bad Kings*? Not just the spark of the story, but the wonderfully rich and varied voices of the seven characters who tell the tale?

**Susan Nussbaum:** For me, it’s always been about letting disabled characters speak for themselves. The way disabled people are represented by the dominant culture is most always as a foil for the nondisabled protagonist. They’re in the story so the nondisabled person “can become a better person.” Once the disabled character fulfills that role, they’re usually killed off, miraculously cured, or institutionalized.

Here’s an example: The movie *Million Dollar Baby* is based on a woman named Katie Dallam who learned how to box and early in her career sustained a traumatic brain injury in



the ring. The first thing Hollywood does is trade in the head injury for a spinal cord injury, making the character more accessible to a mass audience. Then they kill her. But first they lay in this very subversive storyline involving her begging Clint Eastwood to kill her, or “euthanize” her. That’s big in Hollywood: *Now that I have a disability, I can’t go on!* type of garbage. It’s a strategy that solves that pesky problem of what to do with the disabled character once they’ve outlived their usefulness. Meanwhile, Clint Eastwood has become a better person, as opposed to a killer, because she begged him to do it. And they all win Oscars and live happily ever after.

Now the real irony here is, Katie Dallam is alive and well somewhere in Kansas, working as a painter. Not a house painter but a very gifted artist. Did she recover from her injury? No. She will always be dealing with the aftermath of that. Check out her work online.

So I’m always interested in giving a true voice to disabled characters, who are multidimensional, sexual, capable human beings with good senses of humor—and who sometimes become overwhelmed and depressed, like nondisabled people. But they are as unlikely to kill themselves as nondisabled people. What disabled people are up against is not simply the disability. If only that were the case! No, the really disabling problem is the oppression that rains down on us *because* of the disability.

And because I know lots of disabled people of all stripes and all ages, and live with a significant disability myself, and have a

good ear for language, I feel like I could write characters that properly represent. I would be very surprised if there was another book out there by a disabled fiction writer that contains multiple disabled characters. Not to brag. Not at all. But that's how rare it is.

**Durrow:** I had no idea that was the story behind the movie. Wow. And yes, I'd say you have a terrific ear for language—each character's voice is distinct and also funny. Every character—in particular the ones with disabilities—has a healthy sense of humor and a certain optimism that I don't think I've seen in other stories about disabled characters.

You've also created truly memorable characters. I'm thinking specifically of Teddy—I swear I can see him in his rumpled suits so clearly—and Pierre. Those two characters stole my heart. I don't want to give anything away, but were the characters based on real stories you knew of or read about?

**Nussbaum:** No, Teddy and Pierre were total inventions. But I know it feels true, because Pierre is one of many thousands just like him. He's based on research and knowing people. The thing with Teddy is, when I first became a crip, I was surprised to learn how *totally* wrong, wrong, wrong I was about that entire group. I now know many people with intellectual disabilities, and I am often questioning the value of IQ tests. It's absolutely meaningless in terms of personal relationships. IQ impacts a person's learning, for sure, and their skill level, et

cetera. But otherwise, they have gotten a very raw deal, public acceptance-wise. This whole “he has the mental age of a five-year-old” thing is pure vicious, ignorant horseshit. Yessie, however, is based on someone I know.

**Durrow:** You bring up something that I think a lot of people have a hard time asking. What is the right term to use when talking about someone with a disability? You say “crip,” but all the characters in the book have a different way of describing themselves. I think the book is very much about the ability to name oneself.

**Nussbaum:** Yeah, I personally use “crip” in certain contexts, mostly with other crips. Here’s the rationale behind it—like other minorities, we’ve appropriated some terms that represented a time when that term was used to denigrate us. For disabled people, the word “crip” is like a secret handshake. I went to Cuba once and met a bunch of disabled Cubans, and we asked them if they had a word in Spanish that was equivalent to crip. They told us *cojo*, which means “lame,” roughly. So one of my disabled American friends started the Cojo Club. We had this ridiculous gimpy wave. We were fairly drunk at the time.

But I totally get your deeper point about naming oneself. It’s all about claiming identity. And that very thing is so important, especially for people who might think their identity as a disabled person isn’t such a great thing. Yet, however much

we would like to name ourselves, we have already been named many times over by the dominant culture. “Cripple” turned into “feeble-minded” turned into “handicapped” turned into “handicapable,” “differently abled,” “challenged,” et cetera. I mean, I would hate to think I’m “handicapable.” If that was the vogue term for disability, I’m pretty sure I’d call up Clint Eastwood and ask him to come over and euthanize me, ASAP.

Anyway, it’s understandable that people are afraid of saying the wrong word and pissing off some disgruntled crip. I often hear people describing a “handicapped disabled” person, trying really hard not to offend anyone. Just covering all the bases. So the characters in the book mirror that confusion. Even the disabled characters get confused.

But, to answer your question at last, if I were a nondisabled person, I would refer to disabled people as “disabled.” Just “disabled” is good.

**Durrow:** What does the title of the book mean? I know it’s used in the book, but is that a saying?

**Nussbaum:** The title comes from an article I read while doing research for the book. A young boy lived in an institution somewhere in Illinois, I think. I don’t remember the name of the place. The boy was in the institution’s van, accompanied by two aides; one was driving, the other sat in back with the boy. The boy kept trying to stand up out of his seat. So the aide put him facedown on the backseat and sat on him. This

kind of “takedown,” as they are called, is quite common, although they’re illegal in many states. And they’re supposed to be done with two people, so someone can hold the child’s ankles while the other one straddles the kid. Anyway, the aide who was driving later testified that he saw the boy was struggling, and he heard the other aide say, “I can be a good king or I can be a bad king.” At some point, the boy became unable to breathe, and he died.

It became the title because it reminded me of how, when it comes to kids, the adults have all the power. And when the adult in question has no emotional connection to the child, and the child’s welfare is turned over to that adult—as is the case in many institutions—terrible things can happen.

**Durrow:** This is a book about issues, but it’s also a really good story—I read the book in almost one sitting. How much of the story is your story?

**Nussbaum:** My biggest worry is that people will shy away from reading such a book because it will be too sad. But it’s not sad. The characters are juicy enough and funny enough, I think, to guide us through the dark places. I think it’s important for the characters to be on the reader’s side, if you know what I mean. Important in this book, at any rate.

The book is not my story, but the voice of Joanne is my voice. What the character does and what happens to her is not my story. I never worked in a nursing home. I never stayed

holed up in my apartment for twelve days straight. I did use my own experience to flesh out Joanne. The details are me—why she hates manual wheelchairs, her fear of spiders, et cetera. The other characters' voices are either amalgams of people I know or once knew, or total inventions. But, again, that's the voice, not the story.

**Durrow:** I walked away from the book with the powerful message about the corruptibility of institutions for the disabled, but at the same time it wasn't just the institution that was failing the kids. It was almost as if the kids lived in different fiefdoms depending on who the good-king caregiver or bad-king caregiver was—even the well-intentioned caregivers get it wrong. I was really horrified by that. What does that say about solutions to these problems? This is not to say there is a single solution. But I am so glad your book is raising new questions. What do you hope the story will do for readers?

**Nussbaum:** Some of the characters struggle with their culpability, but that's because, I think, we all tend to blame ourselves for outrages that are really systemic. That's why I think all institutions are almost a medieval concept and need to be done away with, once and for all. A nursing home such as the one I describe is set up for failure. The aides are underpaid and overworked because it is good for the bottom line. It does no good to blame ourselves for so many of the dire problems that

face us, because we look for the real culprit in the wrong place. *I should have known* or *If only I had done whatever* will never be a path to addressing real societal problems.

I don't aim to convince readers of anything in particular. Believe it or not, I hope readers will find the book entertaining and enlightening.

**Durrow:** What are your writing influences? Again, the voices are so clear, the dialogue really spot on. That's your playwrighting background, I'm guessing. What inspires you to write? When did you know that writing was your calling?

**Nussbaum:** I love a lot of writers, but I can't say they've influenced me. Well, they've influenced me to love books. But I can't compare myself to other writers, because I wouldn't dare. I feel like I'm the kind of writer who uses what she has—for me that's a good ear and the fairly unique perspective in fiction of knowing the world of disability. And I have the desire, and the discipline.

When I get an idea, I'll start collecting things—articles, books, maps. That might go on for years before I decide to plant myself in front of my computer. It's a sense of being ready and really wanting to communicate. And, of course, having time.

Writing for me is an attempt to embrace readers, to reach out to them and tell them about something that's meaningful

to me. I imagine a stranger's eyes on pages I've written. It's a weirdly intimate relationship. I hope I'm not reported to the Writers Special Victims Police for that.

**Durrow:** You write from the perspective of several characters of different races and ethnicities, and also from male perspectives. How did you approach writing those characters? Did you feel any obligation or discomfort in inhabiting their consciousness?

**Nussbaum:** I do feel an obligation to do right by the characters. I don't think I'd use different races and ethnicities if I didn't spend a good amount of time with people who are all over the map, so to speak. But it's a delicate thing. You have to be very specific, as you know. And when you overstep, even if it feels right to you, you need a good editor to save you from yourself. I hope readers feel each character has his or her own voice and not some generalized voice that sounds like what a white female would write. Excuse me, white female crip.

**Durrow:** I have to admit, your book made me cry—and I love that. Yes, I was heartbroken, but I also cried because I was heartened to see some of the characters find a measure of hope and agency. And when I was done with the book, I missed them. I mean, I have thought about them and wondered how they are doing. Do you think you'll revisit any of these characters or write more about their stories?



**Nussbaum:** I'm really not sure if I'll write about them again. I'd like to write about Yessenia again, but I've been thinking of a topic that probably doesn't have Yessenia in it. I don't know. Maybe I can sneak her in there somewhere.

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## Questions for Discussion

1. Discuss the title of the book, and the passage that it comes from (page 135). How does this title relate to various characters in the novel?
2. Discuss the relationship of Jimmie and Yessie. What does Jimmie derive from their relationship? What does Yessie get from Jimmie?
3. How do the disabled characters in this book compare with disabled characters in other books you've read?
4. Why do you think the author used a first-person narrator approach to telling the story?

5. Is it unusual to hear disabled characters tell their own stories? Why or why not? How might this impact the way you view disabled people in real life?

6. How does Joanne's perspective on things change over the course of the novel, and why? Does she think differently about love? About her disability? About her ability to change things?

7. The book makes the argument that institutionalization is cruel and inhuman. Why does our society continue to rely so heavily on institutionalization as a resource for disabled children?

8. The book makes the argument that abuse and neglect are a natural outcome of the institutional structure. Do you think institutions such as the Illinois Learning and Life Skills Center are still reasonable living alternatives for disabled people? What are some other possible alternatives to institutionalization?

9. What role does paternalism play in the lives of disabled people? Can you give some examples from the book?

10. The book talks a lot about jobs: job discrimination, jobs with low pay, overwork, relationships with coworkers, past jobs, and even possible future jobs. How important is your job in your life? Since more than 70 percent of disabled people experience chronic unemployment, how might this affect their adult lives?

11. If you could predict what some of the characters' lives would be like ten years from now, what might they be doing and where would they be? Yessenia? Jimmie? Louie? Pierre? Mia?

12. There is frequent debate concerning whether white writers can authentically represent characters of other races in their work. Disabled people often complain that books written by nondisabled writers can't authentically represent disabled characters. Considering this book and others, what's your opinion on this issue?



SUZANNE PLUNKETT



Susan Nussbaum's plays have been produced at many theaters. Her play *No One As Nasty* is included in the anthology *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights*. In 2008 she was cited by the *Utne Reader* as one of "50 Visionaries Who Are Changing Your World" for her work with girls with disabilities. This is her first novel.





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**Winner of the Bellwether Prize for Socially Engaged Fiction**

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