

Interview with Rachel Simon

WG: Rachel, *The Story of Beautiful Girl* is an unusual love story in that it centers around two people with disabilities. Other than, *Geek Love*, I can't immediately think of another novel that does this. I'm sure you are asked this often, but what motivated you to write the story?

RS: There are so many reasons that I could spend hours responding to this. But I'll try to be succinct.

I'm the sister of a woman with an intellectual disability. Beth is only eleven months younger than I and, thanks to my parents' strenuous objections to any suggestion of institutionalization, she was raised at home with our two other siblings and me. As a result, I never knew life without disability and I never wanted to. I loved my sister and enjoyed her company. Because I also shared my parents' belief that she deserved the same rights and opportunities as everyone else, I was aware from a very early age that we lived in a bigoted society where people with disabilities were mistreated, mocked, segregated, prohibited from living an ordinary life, and ignored - and I was very angry about it.

I started writing when I was still in grammar school, so I was the kind of kid who really cared about the books we read for English classes. And I realized very early on that we almost never read anything that included characters like my sister, or who had any disability. The few exceptions were usually stereotypes, symbols, or catalysts rather than full, rich characters. Inevitably they were also the only character with disabilities in the story, and inevitably they came to a horrible end. This always struck me as phony and maybe even mean-spirited. I used to think, Who made these rules? Why does everyone follow them? It made me as mad as the bully who said the r-word, or the waitress who'd ignore Beth and talk to me.

When I was a teenager I began writing stories that dealt with disability. Sometimes my narrators were sisters and other times they were people with disabilities. This wasn't the only kind of writing I did but it was a recurring aspect of my work. I didn't start trying to publish anything until my late-twenties. I began with submitting stories, and as luck would have it, I sold a collection of short stories to a major publisher very soon after I began publishing stories. This put me in the unusual position of writing stories for placement in both magazines and my book, as I was given a period of time to add to new stories to the collection. To my surprise and dismay, one of the stories I liked best had the most trouble finding a place in a magazine, as well as acceptance by my book editor. Based on something that really happened to my sister, it was about a woman with an intellectual disability who works in a sheltered workshop where a pair of conjoined twins also come to work. I loved the story but couldn't find a magazine that would take it. My book editor said she'd take it as long as I switched it from first person to third, saying, "I can't relate to this. But if you distance the reader just a little with third person, it might paradoxically help the reader feel closer." I reluctantly did as she asked and the story came out in the book.

But the experience made me realize that editors in both magazines and books were not going to be won over very easily. This only added to my youthful anger about bigotry. I wrote a few more stories that dealt with similar material and had just as much trouble finding homes for them. One, which my agent sent around, about an aging father coming to terms with his daughter's budding sexuality, was rejected for being "just another disease-of-the-week story." Disgusted and furious, I set aside the dream of writing this kind of material for the time being. I published two more books that barely touched on anything disability-related.

Then my sister Beth fell in love with riding buses. A newspaper editor at the *Philadelphia Inquirer*, for whom I was doing freelance commentary, found out what Beth did - and actually assigned me to ride with her for a day and write a piece about it. That alone was a shock, as was this: when the piece came out it was extremely popular, ultimately coming out around the country and leading me to write up a proposal for a book. Although some editors did not understand the proposal at all, it did land at a prominent house. I realized the tide might be turning, at least with some people in key positions.

The resulting book, a memoir that came out in 2002, *Riding The Bus With My Sister*, ended up becoming a national bestseller and opening doors for other disability memoirs. It also led me to do a lot of public speaking around the country about the issues I addressed in the book. And it was while I was doing those talks (which I'm still doing) that I started to think of the wealth of stories that weren't at all like my sister's that needed telling. At first I thought about doing them as nonfiction, since *Riding The Bus* had moved my career in that direction. But the limitations of nonfiction were too severe. I couldn't write things I didn't know as memoir, I'm not a journalist by trade, and in any event I wasn't finding willing subjects for a book. Most importantly, I came to realize that - ta da! - if I turned back to fiction, I could return to writing work from the point of view of people with disabilities. I could also write from more than one point of view. The idea was very exciting.

All that said, I didn't plan anything about *The Story of Beautiful Girl* - not the multiple points of view, not the storyline, not the characters, not the love story, nothing. For a few years before I began it, I did think I should try to write something that addressed institutions and the move into community living, but I had no idea how I would do that. Then I lost a teaching job due to a departmental restructuring, and I was so sad that I decided not to look for more work, but instead to sit down and see what I could write. I literally put my pen down - and suddenly I was writing *The Story of Beautiful Girl*." And as the pen moved forward, the book just naturally took on multiple points of view, focusing on two characters with different disabilities who are in love with each other. I did use third person, though that was less from what my editor said years before and more because I'd already written one chapter - from the point of view of a character without disabilities - in third person. So it was more for consistency than distancing a reader.

I should add that by the time I began *The Story of Beautiful Girl*, in 2007, I not only thought the publishing world might be more receptive than it had once been, but that the success of *Riding The Bus With My Sister* would make editors more likely to believe that there were tons of readers out there eager for this material. Ultimately, as I wrote, the love story became the core of the book, which made me think that even those editors who might still cling to medieval attitudes would see the book as more than "just another disease-of-the-week story." I'm happy to report that they did, and in fact the people at my publishing house were so over the moon about the book that they worked hard to get it a lot of exposure. The result was my first New York Times

bestseller.

The whole experience with this book has made me very hopeful. Bigots can wake up. Society can transform. Not that we don't still have a long, long way to go, but it seems that anger, when held onto long enough and funneled into art, can play a major role in getting us there.

WG: *Wordgathering* was begun five years ago by writers at Inglis House in Philadelphia. I'm not sure if you know this but Inglis House was originally called The Home for the Incurables, so I can't help but asking if there is any relationship between Inglis House and The Home for the Incurables and Feeble-Minded in your novel. As a follow up, I'd like to ask what type of research about institutional life it took for you to be able to write *The Story of Beautiful Girl*.

RS: I did indeed know that Inglis House was originally called The Home for the Incurables, and in fact it was partly in homage to Inglis House that I named the institution in my book *The Pennsylvania State School for the Incurable and Feebleminded*. The way this all happened preceded the writing of my book by several years.

After my memoir, *Riding The Bus With My Sister*, came out, I kept wondering what I'd do for my next book. I knew I wanted to focus in some way on relationships between people with disabilities, and my original hope was to have a romantic approach. (My sister had been in a romance for many years, but I'd already covered that in *Riding The Bus*.) I was still oriented toward writing nonfiction, so sometime in the year or two after the release of *Riding The Bus*, I send out an email to people who'd gotten in touch about the book and asked if they had any relationship stories they wanted to share with me. All the responses I received focused on friendship, not romance. I did follow up on several of these, and met several people who I liked very much. (One, Nick Pentzell, a man with autism who communicates through a keyboard, became a writing student and then a friend.) But for whatever reason I wasn't finding love stories.

Then one day I had the good fortune of spending a few hours with a young photographer, Mark Stehle. I met him through a friend of a friend, and hired him to photograph a portrait that an artist who rode the buses with my sister had painted of her. During that photo shoot, he mentioned that his father, Bernard Stehle, who was also a photographer, once put out a book called *Incurably Romantic*, about love stories at Inglis House. I believe the book was out of print by then, but I hunted around online and found a copy. It was the treasure I'd been looking for - stories of many couples, all of whom had disabilities. The book also moved through many years, with different time periods being indicated by photos that showed the latest name for Inglis House. I somehow hadn't realized that any place ever used words like "Incurables" in their name, and I was shocked and saddened to see this. I also saw how many of the relationships changed over the course of the book. It was moving, eye-opening, and validating; I saw that my idea of writing about romance was true, important, and real.

However, as I mentioned in the last answer, I didn't have a story for awhile. I did, though, realize that I wanted to write my story of romance in fictional form, as I came to see it would be too difficult to find a couple to interview. I suppose I could have contacted some of the people in Bernard's book, but since he'd already written about them, and since I'm not a journalist anyway, I didn't really consider that option. As a result, I just let the idea of writing a love story float around inside me for years.

In the meantime, I also started to get drawn to information about institutions. I couldn't figure out how to write about them - the material seemed to vast, and my personal knowledge too limited. But I was interested nonetheless. A few friends directed me to some excellent titles, which I mention in the back of my book. Another friend asked me to help her with some edits on a documentary she'd made about her brother, who was in Letchworth. (This film, *No Apology*, is also in the back of my book.) I remembered coming across *Christmas In Purgatory* when I was younger, and looked it up again. Whenever I was on the road for talks related to *Riding The Bus With My Sister*, I paid extra attention to the stories of self-advocates, family members, and former staff. And I came across the very powerful book, *God Knows His Name: The True Story of John Doe No. 24*, and read it in one sitting, crying the whole time.

These resources all swam around inside me, along with the vague idea of a love story, for a long time. I had no idea they would intertwine into a single book, and probably if I'd tried to plan it out in advance they wouldn't have. But when I began writing, everything fell into place. And because my original resource for love stories (aside from my sister's and her boyfriend) came from Inglis House, I wove its history into the name of the school.

In fact, when I first met you at SDS in Bethesda a few years ago, I was very excited to know of your connection to Inglis House, and I wanted to tell you this whole story. It turned out that we didn't get any time to speak, but probably even if we had, I would have held back. I'd just started writing my book, and I don't talk about what I'm writing when it's in first draft.)

As things turned out, I did eventually meet self-advocate Debbie Robinson and her husband, Frank Yurick, on several occasions, and they were very eager to share their love story with me. By then I'd moved onto fiction, so I didn't follow up as I would have before I began writing *The Story of Beautiful Girl*. That said, I still hope that someday I can interview them. I'm sure they have much to share.

I will add one more thing, and that's that I did a lot of other research as I was writing the book. Mostly this took the form of conversations with people who were already friends, and who would therefore be willing to share insights with me without needing to know the whole story. Beth Mineo, a friend who now runs the Center for Disability Studies at the University of Delaware, helped talk me through many of the communication issues that run throughout the book. Kathleen McCool, a friend who I originally met when she was helping bridge the divide between transit and people with disabilities, helped me brainstorm the scenes involving the character of Sam. Dr. Dan Gottlieb, a friend and fellow writer, reviewed the Sam chapters to help me ensure that I wasn't saying anything foolish about people with spinal cord injury. Scholar and friend Susan Burch reviewed the whole book, checking in particular for how I handled the character of Homan, who has some things in common with a man she wrote a book about, Junius Wilson. Allison Carey, also a scholar and friend (and fellow sibling) reviewed the whole book as well, checking details that related to the history of people with intellectual disabilities. And throughout it all I also thought about Nick Pentzell, since he communicates in ways other than spoken words, and Homan and Lynn timer do, too. I knew from his writing that his inner life in incredibly rich; and therefore I knew that Homan's and Lynn timer's could be rich, too.

WG: So the idea for Homan being a John Doe who was given the designation Forty Two, came from *God Knows His Name: The True Story of John Doe No. 24*?

RS: Yes. I was very moved by that book (written by a reporter named Dave Bakke) and felt the urge to do what I could to help give John Doe No. 24 the life he was not allowed to live. As you can see, I flipped the numbers. Again, this was a way to pay tribute to the original source of the material. I actually did this kind of thing throughout the book, with side characters, street names, and locations. For instance, an important scene happens outside the Berkeley building in which the Independent Living Movement began.

WG: You mentioned that Susan Burch, who is well known in disability studies circles, reviewed your book, especially with an eye to the character of Homan. I'm curious to hear what her reaction was and if she gave you any advice or insights that you made use of. As a corollary to that, I also like to ask if you've had any feedback from members of the Deaf community and what their feelings were about how Homan was portrayed.

Susan was immensely helpful. She commented on a number of very specific details, all of which I adjusted accordingly and all of which she reviewed. She liked the book a great deal, and in fact gave me an endorsement, which is on my website: "Vivid, engaging, and deeply human, *The Story of Beautiful Girl* illustrates the powerful impact that race, language, gender, place, and disability have on our lives. As in "real life," poignant moments of misunderstanding and stigma, and oppression and exclusion, exist side-by-side with experiences of connection, empowerment, and liberation. This imaginative work seeks tangible ends: social justice, inclusive community, and love. A richly important book."

I have other endorsements from people in the disability community on the site:

<http://rachelsimon.com/the-story-of-beautiful-girl/testimonials.php#endo>. I haven't been keeping that section updated, so I'll add one more here, from Simi Linton: "Rachel Simon has written a compelling and wonderful book. *The Story of Beautiful Girl* grabbed me instantly and I was swept up in the story. At the end I realized I had been given a lesson in disability history not easily forgotten - the transition from institutionalization and deprivation to a more equitable and integrated world for disabled people. A great example of that real history is revealed in a subtle and poignant moment in this work of fiction: The anticipated visit of the famous playwright and his movie star wife to the institution."

Back to your question. I really wanted to show the book to people in the Deaf community, and I pursued all the avenues I could think of. Mostly these were hearing people who were intimately connected to Deaf individuals or schools. Only one of those connections bore fruit, I'm sorry to say. That person, who went to the Tennessee School for the Deaf, considers himself deaf, not Deaf. Nonetheless, he felt that the story accurately portrayed the character of Homan/No. 42. In particular, he commented on Homan's way of assigning descriptive labels or conceptual labels to feelings, objects, and people, such as "Beautiful Girl," "the Tingling," "the Snare," and "Roof Giver," all of which seemed in keeping with what he thought Homan's inner life would be. In addition, this man felt it realistic that, given Homan's situation (and his use of a sign language other than ASL), he had a paucity of friends in the various communities in which he found himself, and very few people interested in learning his way of communicating. The one thing that troubled this man was that he lived in Pennsylvania in a time period that overlapped with the time period in the book, and he was very disturbed to realize (or remember) how people were being treated not far from him in his own lifetime.

I have sent notices about the book to *Odyssey* magazine at Gallaudet, but I'm not sure if they were

ever read or followed up on. I realize that my being a hearing person is a hindrance for connecting with that community. I'm hoping that, over time, the book finds its way there even without my help.

On a separate note, I want to mention that the publisher will be sending me on a book tour in late February 2012, when the paperback comes out (with a different cover, which I can show you if you'd like). I do hope to meet anyone who might be interested in my book while I'm on it - or while I'm doing my usual talks, which are scheduled right now through the end of April. I will have everything posted on my website soon.

WG: I'm sure you're asked this question a quite often, but I'm wondering if the writing of *The Story of Beautiful Girl* has changed your perceptions of disability in anyway. If so, how? Obviously, in your experiences with your sister and all of your previous research you came the writing of the book with quite a background, but still....

RS: I've been struggling to answer this question, as I'm uncertain about just when my perceptions changed, as well as how I can articulate the changes. I know that every time I speak with a person with disabilities (every day) or read articles, blogs, and books written from the point of view of people with disabilities (at least a few times a week), my knowledge and therefore perceptions expand. This has been true for many years, including the several when I did the formal and informal research that preceded the writing of this book. But I'm not sure how to put these changed perceptions into words.

So perhaps I can address your question in a different way. During the years when I was doing my formal and informal research, which were mostly from the release of *Riding The Bus With My Sister* in 2002 until at least 2007, when I began writing *The Story of Beautiful Girl*, I read everything I could about the disability rights movement and made friends with several people who were and are very involved. As a result, I became very much aware of the idea of motto Nothing About Us Without Us, which is used by disability activists to demand that they have full participation and active involvement in every program, policy, law, etc. that affects their lives. I felt great respect for that idea, and all the more so when I read critiques of policies, studies, books, etc. done by people without disabilities, and saw how readily they fell into the same old paternalistic, pitying, super-crip, or medical model patterns. For a long time my awareness of Nothing About Us Without Us made me think that I shouldn't write about people with disabilities from any point of view other than my own, since, while I might be the sister of a woman with an intellectual disability, and have walked beside her all my life (esp. since we're only 11 months apart), I haven't *been* her.

As time went on, I started to feel more and more drawn to writing about material I hadn't lived, and I therefore turned to considering fiction. Naturally, this led to my looking at the other work that was out there. There are a number of writers with disabilities who are writing fiction, such as Ann Finger and John Hockenberry, and they're terrific. But the bulk of what I came across was nonfiction. And when I looked at the syllabi for writing classes taught by fellow fiction teachers (I was teaching in a creative writing program at a college at this time), I saw work that addressed ethnicity, nationality, gender, class - but not disability. This angered me greatly, and while I did include some short stories from Kenny Fries' anthology in my own syllabus, I felt that I, and all my colleagues, were letting the students down by not having a lot more. It then became very clear to me that there needed to be way more fiction that dealt with characters with disabilities - written

not with the typical, patronizing mindset, but with a greater awareness. Yet for a long time I pretty much took myself out of the running as a candidate for writing disability-related fiction.

Then I had a few conversations with people with disabilities who'd become friends, and shared this conundrum with them. Unfortunately I can't remember specific names, since these conversations have slipped into the fog of the writing process, but I do know they were already people who'd read *Riding The Bus With My Sister*, and who therefore had a sense of my writing style, commitment to accuracy, and embrace of the ideals of the disability rights movement. They encouraged me to try my hand at fiction, even while being aware of *Nothing About Us Without Us*. I remember being very emotional in these conversations, and saying I wasn't sure if my contribution would be considered legitimate. And I remember them continuing to encourage me, even with my reservations. One even said, "You're an honorary person with a disability," though I wasn't sure if others would agree.

After all of this, I recognized that if I did start on the path of fiction, I would have to be extremely conscious of all the ways that, as an able-bodied person, I could totally blow it. But I also recognized that it was important that we have more fiction out there, and that, since I'd already published two books of fiction, had had a breakthrough book with disability-related nonfiction, and was deeply involved with the disability community on a personal, social, and professional basis, it might be worth my trying it out. I knew I could always trash it, and that if I didn't, I would have to vet it with people who could set me straight. So when I began the writing itself, I proceeded with all of this in mind.

As I mentioned in an earlier answer, I did show the book to several people in the disability community, including Susan Burch and Simi Linton. Other early readers included Joy Weeber and Julie Petty. Their comments were very helpful, and their enthusiasm for the book very validating.

All that said, I'm still quite aware of *Nothing About Us Without Us*, and I realize that my not having a disability might keep some people from wanting to read my book. I do understand this, and I only hope that, if I continue to write fiction involving characters with disabilities, I might someday be seen in a favorable way.

WG: The other day among the many catalogs coming in the mail this time of year I received one from Bas Bleu, which chose your book as one of those they were recommending to readers for Christmas. It was a nice surprise to see your novel popping up in unexpected places. In terms of marketing, you've mentioned already that you'll be doing a book tour in February 2012 and that you have a paper back version coming out. Is there anything else you have planned for getting the word about *The Story of Beautiful Girl* out?

RS: I hadn't known about Bas Bleu! Thanks for telling me.

I've been working really hard for the past year to spread the word about *The Story of Beautiful Girl*. I've been very lucky because I haven't been alone in my efforts; the publisher has wanted this book to be a big commercial bestseller since they acquired it in 2010, and they've put a lot of behind-the-scenes work, and money, into promoting it. This has led to them doing things far beyond my reach, like lots of print and online ads (including expensive ones in the *New York Times* and *New Yorker*), lots of galleys going to reviewers, a so-called "pre-sale tour" where I met

influential booksellers around the country prior to publication, and a book tour this coming February when the paperback is released. (They were almost certainly responsible for the mention in *Bas Bleu*, too.) I have never had this kind of attention before from a publisher, and the fact that it's happened with a book where the two main characters have disabilities, and where the story could help turn the public against institutions in favor of community living, has been extremely heartening to me.

But the publisher is a mainstream, commercial house, and they don't know much at all about what they call the niche market. So I told them long ago that I would do everything I could to spread the word in the disability community (a term I use loosely and broadly), and I have. I do a ton of social media, including a website <http://rachelsimon.com/>, blog <http://rachelsimon.com/blog/>, Facebook (Rachel Simon), and Twitter (@rachelsimon). I visit large numbers of book clubs, writing groups, and high school & college classes via Skype video call. I do talks in an ongoing way all over the country, where most of my audiences are people with disabilities, their families, and those who provide support. Whenever I travel for these talks, I try to set up additional meetings with people in the local disability community, where I can get to know them, see their lives, and talk with them about my book. I'll speak to any politician I can get access to. I'll speak to any bookseller I can get access to. I'll do any interview for print, podcast, video, radio, TV. You name it, I'll do it. I've never been one to sit on the sidelines when I publish a book, and even if I were inclined to take it easy, the material in this book is just too important for me to let that to happen.

I hope readers of this interview will take a moment to check my website so they can learn if I'll be in their neck of the woods any time soon. The link is: <http://rachelsimon.com/appearances.php>. My book tour is in February, and my public speaking is currently scheduled through the spring, with more events getting listed as each one gets set. If you do make it to one of my appearances, I hope you'll come up to me, and let me know that you're there because you saw this interview in *Wordgathering*. I will let Mike Northen know - and it will mean a lot to me.

WG: Rachel, I really appreciate the time you've taken out to give us this interview, especially given the hectic schedule with your new book just out. Unlike most literature in which disability is central, *The Story of Beautiful Girl* has a mainstream publisher, so anyone interested in reading your novel should have no problem finding it in major bookstores. Best of luck with your tour.

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