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## With 10-year edition of 'Riding the Bus' comes subtler understanding of intellectual disability



(Luigi Ciuffetelli)  
Author Rachel Simon

By Ron Charles,  
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Rachel Simon knew that having a sibling who has a serious intellectual disability had changed her life. But she had no idea that writing a book about the experience would change her life again.

Recalling those early days, Simon says, "I allowed myself only the hope that the book might be well-received and sell enough copies to earn a modest royalty check — \$50, say, or, dare I dream it, \$100."

Turns out, she wasn't dreaming nearly big enough.

On Tuesday, her bestselling memoir, "Riding the Bus With My Sister," will be reissued in a special 10-year anniversary edition (Grand Central; paperback, \$14.99). The book recounts Simon's efforts to understand the life of her sister by tagging along as the sibling spends her days riding city buses around her home in Pennsylvania.

For both Simon and her sister, Beth, it has been a great ride. Now a staple text among families, teachers, social workers and anyone else interested in the lives of people living with disabilities, "Riding the Bus" has remained continuously in print, and in 2005 it was adapted into a Hallmark Hall of Fame movie directed by Anjelica Huston.

The 10-year anniversary edition includes three new essays: an update on Simon's life, a reaction from Beth and commentary on the current state of the disabilities community.

"My sister's doing great," Simon says from her home in Wilmington, Del. "Spoiler alert: She's still riding the bus!"

But over the past decade, many things have changed for Simon and her sister — and other people in similar situations. For one thing, Simon says, "When I wrote the book, we used the terminology 'mental retardation,' but now we would say 'intellectual disability.'"

That shift in the language signals other, more dramatic improvements. The institutions where so many people who have intellectual disabilities were warehoused for decades are being dismantled (often under court order), and the residents are being moved to small group homes or independent-living arrangements that encourage greater freedom and dignity.

Beth's family had always opposed placing her in an institution. "We were fiercely behind the idea that Beth belongs in the world," Simon says. And now state and national policies are quickly catching up with that enlightened attitude. "There's been such a rise in the idea of self-determination — that people with disabilities have the right to choose how they want to spend their time."

One of the many things that surprised Simon was how the experience of observing her sister interact with bus drivers and other passages changed her own attitudes. "In the process of riding with her," she says, "I recast my understanding of what she was doing as an exercise of her civil rights. The book is really about my enlightenment — coming to terms with her rights."

And she has great advice for family members and caregivers, too. "It's very easy when you look at someone with a disability who loves something to call it their 'obsession,'" Simon says. "But you've got to rename it their 'passion.' That changes everything. Once I did that, it changed my relationship with Beth — and all my other relationships, too."

Now in addition to her full-time work as a public speaker and advocate for people living with disabilities, Simon finds herself constantly promoting buses, subways and light rail. As she travels around the country, people sometimes tell her, "Oh, we don't need public transportation around here because everybody drives!"

To that naive generalization, Simon emphatically says: "No! There are people everywhere who will never learn to drive. By not having transportation everywhere, we sentence those people to house arrest or their families to being chauffeurs for life. Public transportation is a key component of an independent life for people who are older, people who are lower income."

For Simon and her sister, the journey continues. And this 10-year anniversary edition of her memoir is another good chance to get on board.