

Form Follows Content: A Conversation with Authors Paul and Judy Karasik

Paul and Judy Karasik's *The Ride Together: A Brother and Sister's Memoir of Autism in the Family* joins several thought-provoking books published recently by family members, such as Rachel Simon's *Riding the Bus with My Sister*, Dan Mont's *A Different Kind of Boy*, and a number of others. *The Ride Together* alternates chapters of illustrated comics by Paul with chapters of text by Judy, so the format is as dynamic as its subject: their oldest brother David.

The Arc recently had the chance to ask the Karasiks about their family's history and their new book.

Q.: How do you think the book can help families like your own?

Judy: It mirrors their own actual experience, it tells how our parents dealt with the things that others deal with, it tells them what the average kids in the family are really thinking. It provides an "explanation" for them to give those outsiders who are clueless.

Q.: We know the numbers of families are high. Are "clueless" people a big audience?

Paul: Most Americans are two degrees of separation from someone with a serious developmental disability but don't know how to relate to them. They can be afraid, or unsure, or freaked out, which is a pain for those of us who are family members – and a tragedy for the people with disabilities themselves.

Judy: The question I got asked most often when I was growing up was, "What's it like to have a brother like

that?" Some of my friends imagined living with David was unimaginably horrible, others imagined that living with David was a precious transforming experience which gave me these brilliant insights into reality. It was neither and I remember wishing I could find a book to give outsiders that would help them understand. This is that book.

Paul: Every family is different and, with us, David wasn't the only difference.

Q.: The book's pretty different, too. If you open up to a chapter by Judy, it looks like a regular book with text. But when you see a chapter by Paul, it's like opening a comic book. Why?

Paul: That's just the way it happened. I'm a cartoonist. I'm also a teacher, and have been for the past 25 years, but I express myself in cartoons. That's my medium. My sister Judy is a writer. She's also worked in various ways to help improve the way services are delivered in communities, but she expresses herself in writing.

Judy: After our father died, we wanted to record the stories of our household, mostly for the benefit of our children and their cousins. I wrote my chapters, Paul drew his, we put the two sets of chapters together, alternating voices. And, after about six years of fighting over what worked and what didn't, we had a book.

Paul: We like the fact that it's strange. Form follows content! When you read the book, or when you meet our family, it seems weird at first, but soon you get used to it. It shows you, too, that there are different ways to communicate; I use pic-

tures, Judy writes, David talks in his special code. All of these ways can be effective.

Q.: David's "code"? What's that?

Paul: He uses formulas, standard statements that get modified to express what he's thinking. For example, he took a character from the old Superman TV shows, a bad guy named Gorilla Watson, and made him into a kind of shtick. You talk about something you care about, then Gorilla Watson threatens it, and then you say what you'll do to stop him. "What if Gorilla Watson comes to the Christmas party?" David will say. And we say right back, "Well, we'll call the police!" It's another way of saying that we all hope the party will go well. There are a lot of things people say to one another in code, especially in families. With David it is just a lot more noticeable.

Judy: We put Gorilla Watson into one of Paul's chapters. He appears and takes over the story. The bad guy doesn't think we're telling the story right!

Q.: Do the rest of you see yourselves in David?

Judy: Absolutely. Like our brother David, we like things to happen on time. We like to have time to do our work, to be busy. We share the same sense of humor, kind of a mocking, silly humor. It seems natural to us that these similarities exist. Genetically, your closest connection is to your siblings.

Q.: Many times in the book, over the forty-five years it covers, we see you

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two being angry at David, or impatient with David, or unhappy being in a family with David. What does your mother make of that?

Paul: Our Mom wants us to be honest. Our job in writing the book was to try to tell the truth.

Judy: It's been hard in some ways to live with David and, on the other hand, our behavior hasn't always been so great for him, either. Quite frankly, I don't think people would believe the positive feelings and moments in the book if the negative moments were missing. That's real life. ■

The Ride Together *is available at* www.amazon.com.

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Family Memoirs

In addition to the materials available through The Arc's Sibling Support Project (www.thearc.org) a number of recent writings by siblings and parents provide different insights on family life and disabilities. Here are some newer titles.

Riding the Bus with My Sister

by Rachel Simon

Rachel's sister Beth is a spirited, independent woman who has mental retardation. For a year, Rachel joins Beth in riding the buses in her city all day long, discovering her sister's life and changing both their lives in the process.

Siblings

By Kate Strohm

Kate, who has a sister with cerebral palsy, tells her story, and the stories of other siblings. She explores how resentment, guilt, grief and isolation can manifest in adulthood as depression, anxiety and other psychological problems and gives detailed strategies for coping and coming to terms with these feelings.

(Published in Australia and available through www.wakefieldpress.com)

Special Siblings

By Mary Mc Hugh

Memories and reflections of growing up with a brother with mental retardation and cerebral palsy are interwoven with the author's research and interviews with more than 100 other siblings and experts. She explores a spectrum of feelings, from anger and guilt to love and pride, to help readers understand issues siblings may encounter in childhood, adolescence, and adulthood.

A Different Kind of Boy

by Daniel Mont, contributing writer to The Arc inSight

Daniel's fourth grade son Alex, a math prodigy who has autism. The Monts use determination and humor to advocate for Alex's services and supports and ensure that he's fully included in their community.

Life As We Know It

by Michael Bérubé

When Jamie Bérubé was born with Down syndrome, he was immediately subject to the medical procedures, insurance guidelines, policies, and representations that surround every child our society designates as having a disability. Jamie's father, literary scholar Michael Bérubé, describes not only the challenges of raising his son but the challenge of seeing him as a person rather than as a medical, genetic, or social issue.