

**Lifelong commitment:** Many adults are woefully unprepared to assume care for disabled siblings

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75% of adults with developmental disabilities live with their families

25% of their caregivers are over 60

Source: The Sibling Leadership Network

58% of siblings say they don't feel financially ready to take on the role of caregiver

34% of siblings say they didn't feel emotionally ready

Source: Easter Seals

Cheryl Resnick was perhaps 7 or 8 years old when she suddenly piped up from the back seat of the family car.

"Mommy, I want you to know it's OK," she told her mother, Ilene Resnick. "When Mommy and Daddy die, I'm going to take care of Adam."

It was a heavy pronouncement, and one Cheryl had come up with on her own. Her teenage brother had classic autism, the kind that would require lifelong supervision.

"Even at that age, she was very aware of what his needs would be and what she saw her responsibility would be," said Ilene Resnick, of Cherry Hill.

"I would always want her to be concerned and to know what's going on with him. At holiday time, I'd want a place for him at her table. But that's different than the day-to-day care."

More than 75 percent of adults with developmental and intellectual disabilities live with their families and a quarter of their caregivers are over 60, according to research compiled by the Sibling Leadership Network, an advocacy group.

Many families haven't made plans or discussed future care with siblings, the group reports. But as their parents age, sisters and brothers are the ones most likely to take over care of their siblings with special needs. They'll have to answer a host of questions regarding guardianship, residency, medical care and finances.

The majority of siblings — 58 percent — report they don't feel financially ready to take on that role, according to a study by Easter Seals. About 34 percent said they didn't feel emotionally ready.

Next Sunday, Samost Jewish Family and Children's Services and the Katz Jewish Community Center will host a workshop in Cherry Hill, featuring a siblings' panel, a lawyer who

specializes in sibling issues and author Rachel Simon. Simon will share her own experiences as the sibling of a woman with a developmental disability, chronicled in her memoir, "Riding the Bus with My Sister: A True Life Journey" (Plume, 2003).

For the past decade, Samost has offered Sibshop, a monthly peer support and education group for the young siblings of children with special needs. But there are no local support groups for adult siblings, said Barbara Abrams, who directs the special needs department at Samost. That's partly why the conference came about. She hopes the event will lead to a sibling support group locally.

According to the Easter Seals' study, less than one-third of sibling caregivers are involved in one.

"The issue is only going to be growing," said Abrams, noting the increasing number of children diagnosed with autism. "I think it's only going to get larger."

Born seven years apart, Cheryl Resnick of Monmouth Junction said she and her brother fought like typical siblings.

"We'd be playing Nintendo and my brother would walk by and shut the Nintendo off and laugh hysterically," said Cheryl, now 30.

"They don't know appropriate social skills. He'd push a button and get a reaction out of me. I would get so mad and start screaming for my mother. She'd yell at him."

Adam folded every piece of paper he could find into airplanes, whether they were important bills or pages ripped from his sister's books. That sent Cheryl running to mom.

"As a parent, what do you say to that?" Resnick asked. "I'd hide my books a lot." The two would lie on their parents' bed and talk, though Adam mostly listened. Yet just as a mother learns how to interpret her infant's cry, Cheryl learned how to interpret her brother's moods from the tone of his voice.

When she was just a 5-year-old, Pam Rosenberg of Marlton learned sign language so she could communicate with her little brother, Scott. The boy was one of the first in the country to be diagnosed with Fragile X syndrome, a genetic intellectual disability that caused speech and learning delays.

Scott was hyperactive and often anxious. His arms were covered with his own bite marks.

"As a child, I didn't know anything else because he's my only sibling," said Rosenberg, now 39. "As I got older in elementary school, I would notice other kids making fun of him."

“I was constantly defending him.”

Today, her 36-year-old brother doesn't drive, read, write or cook. But his long-term memory is excellent. He lives in a group home, has a job and competes in the Special Olympics. His parents, who are in their mid-60s, are his guardians.

But Rosenberg wants to learn the legal and financial details she'll need to understand one day. She plans to attend the sibling conference next week.

“Knowledge is power for me,” Rosenberg insisted. “I really don't meet that many people who have the type of upbringing and lifestyle that I had.”

### **All in the family**

The possibility of future caregiving affects not only siblings but their spouses and children.

When Tovah Freedman Kurlansik and her husband were preparing to get married, they had a conversation about her easygoing younger brother, Zachary, who was born with Down syndrome. Tovah wanted her fiance to know they might one day be responsible for his care.

“It's always been a thought to me,” said Kurlansik, the stay-at-home mother of a 3-year-old and a 1-year-old. “Where will he be? Will he live with us?”

“Right now, my mother is the director of his care and keeping,” added the 29-year-old, who will be among the sibling panelists. “He lives under (my parents') roof and she's the one who takes him to the doctor and makes the appointments.”

Though Cheryl Resnick's brother is still relatively young, she's already thinking about medical conditions that could crop up in the future, such as diabetes, Alzheimer's and prostate cancer. As coordinator of family advocacy and family services for the Arc of New Jersey, Resnick encounters many siblings who suddenly become caregivers with “no clue how the system works.”

That's why she went into the developmental disability field. A planner by nature, Resnick plunged into the world of advisory councils and advocacy.

“It was originally fear-based,” she recalled. “Oh my God, one day I'm going to be in charge and I need to know what to do.”

Resnick doesn't sugarcoat the job she has prepared for her whole life. She remembers what it's like to be in a supermarket with an older brother who has a tantrum. But that's OK.

“It's my brother,” she insisted. “It's not even a question that I will take care of him.”