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Siblings of disabled face common struggles

Conference provides advice, insight for those becoming primary caregivers

BY CHRIS TOGNERI

Delilah Picart doesn't know when, but someday she will become her brother's primary caregiver.

And unlike most siblings of a person with a disability, Picart has spent years preparing.

"But it's kind of like parenting," Picart said. "You can read all the books in the world, but you never know until it actually happens."

Picart spoke Thursday at

the National Sibling Leadership Network Conference at the Wyndham Grand Pittsburgh, Downtown.

The conference brought together researchers, advocates and families to discuss challenges facing siblings of people with disabilities and to encourage families with a disabled person to start talking now about the future.

"It's a very tender topic," said Don Meyer, director of the Sibling Support Project in Seattle, which helps connect siblings of people with disabilities through online forums. "Parents are understandably reluctant to talk about something as

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Siblings of disabled voice their concerns

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uncertain as the future of a child with a disability. But it's important."

Nearly 5 million people in America have autism, Down syndrome and other intellectual and developmental disabilities. Most of them live at home with a caregiver, often a parent.

When the disabled child outlives the parents, siblings usually are next in line to assume caregiver responsibilities.

Typically, they are not prepared, said Katie Arnold, executive director of the Sibling Leadership Network.

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Picart, 32, of Shadyside, is an actor who recently appeared alongside Tom Cruise in the movie "Jack Reacher," filmed in Pittsburgh.

She said she has always felt a responsibility to look after her younger brother, Eric, 30, who has Fragile X syndrome, which results in intellectual disabilities and social anxiety. He lives in the family's hometown New York City with their mother, Vivian, 71, who is Eric's full-time caregiver.

Wanting to help her mom, but living hours away, Picart began talking to her mother about Eric's long-term care years ago.

"We were on vacation and she said, 'I'm doing all I can so you can live your life,'" Picart recalled. "And I said, 'but mom — he's my brother and I love him.' As his older sibling, I feel like I have a vested interest in caring for him."

That initial talk led to years of further preparations.

"Now it's a question of figuring out all the logistics of slipping him into my life," Picart said.

When families fail to have those sensitive talks, they must make major life decisions hastily during a time of grief, officials said.

They said it's important to include disabled siblings in discussions because while parents assume they would want to be with a sibling, that's not always the case.

"There is a range of ways to remain lovingly involved in the life of a sibling with a disability," Meyer said. "And that doesn't always mean everybody has to live under the same roof."

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Siblings of those with disabilities assemble in Pittsburgh

By Kaitlynn Riely

It's a powerful bond, the relationship that binds siblings together. On Thursday, a group of people who have had that bond tested met Downtown. The Sibling Leadership Network, a national nonprofit organization for siblings of people with intellectual and developmental disabilities, held its daylong convention at the Wyndham Grand Pittsburgh, drawing about 65 people from around the country. Some of them care for their adult siblings, while others plan to do so in the future after the death of their parents. They were in Pittsburgh to talk about their experiences as siblings and to learn more about being caregivers, a topic that is often omitted from caregiving discussions, said Katie Arnold, the network's executive director.

"There's so much focus on people with disabilities and parents in terms of providing information and services and support, and we realized that often siblings were being overlooked," she said, describing the impetus for the network's founding in 2007.

It has grown to 3,400 members and 13 state chapters, including a Pennsylvania chapter based in Philadelphia, and is focused on providing support systems for siblings to share stories and struggles and has advocated for research, policy and services related to sibling interests. A current policy focus is to expand the federal Family and Medical Leave Act, which permits workers to take unpaid, job-protected leave to care for family members, to include siblings.



Delilah Picart

The bond between two siblings is often "an extremely potent, underappreciated relationship," said Don Meyer, director of the Sibling Support Project in Seattle, a separate sibling group. "You can't underestimate it," Mr. Meyer said of the relationship between siblings. "It is truly thicker than water."

It's land, not water, that separates Delilah Picart, who attended the conference Thursday, from her brother, Eric. The 30-year-old lives in New York City with their 71-year-old mother, while Ms. Picart, an actress, author and advocate, lives in Shadyside with her partner, her 7-year-old daughter and her two stepchildren.

Growing up, Ms. Picart was always "the second mom" to her brother. Two years younger than her, he was born with Fragile X syndrome, a genetic condition that results in intellectual disability.

The geographic separation - as well as her father's death two years ago - has left Ms. Picart concerned about what will happen when her mother can no longer care for her brother.

"My biggest worry is where is my brother going to live when my mother passes away?" she said.

She is also concerned that she may not be able to secure for him the same level of care here as in New York, and also be able to juggle her career and her other family relationships.

Knowing she was not alone, and speaking with other siblings who are also caregivers, was a "key" part of the conference, Ms. Picart said. Like her, she said, many of the siblings she met have a take-charge personality but are also compassionate and patient. And, like her, the other siblings have experienced a different type of sibling relationship.

"I take it on because I love my brother and I understand him in a way that only siblings understand," she said.