

Sibling stories

by Liz Carlisle

Three individuals at different life stages reflect on what it's like to grow up with a brother with autism. Although their experiences differ, they all express a deep love for their siblings and an appreciation of how profoundly they have influenced the way they see the world and their places in it.

Roisin "Sheenie" Liew, age 12

"I love giggling with him, tickling him, playing games with him...and just being with him," says Sheenie about her older brother, 14-year old Devin. He was 18 months old when she was born, so "I never knew him any different," she says.

Her parents, Shannon and the late Fah Pow Liew, explained Devin's autism in a way that she understood at an early age. "My mom and dad told me that he had trouble talking because of something that is different in his brain, but he is clever in his own way, and he loves me."

In school, Devin has shaped Sheenie's behavior in a number of ways. "My brother has taught me to be patient with others in school, to show kindness toward others, and he helped me with future actions I would make. For example, if I was talking to a group of friends, I would think about what I was going to do or say before doing or saying it."

Sheenie also credits Devin with helping her make a career choice as a neuro-oncologist and researcher in the field of cancer and autism. This summer she will be participating in a program at the Center for Talented Youth through Johns Hopkins University, where she will study the brain and how it interacts with the body and mind.

Much of the support Sheenie gets as the sibling of a person with autism comes from her family. She is able to share any concerns with them and "whenever something comes up and we need to talk about it, we do." She does not feel that her brother gets any more attention than she does "because my mom favors us both, and not just one of us, so attention is split between us equally."

Living with Devin as he grows through adolescence is not without its challenges, however. Sheenie notes that she is occasionally called upon to look after him but only for short periods of time since he has become more aggressive and angry.

"I would look after him anyway because I love him," she adds.

Sheenie has opportunities to share with others through school and at Devin's sporting events, where she meets the siblings of his teammates.



She looks forward to being part of a sibling workshop, where “I could get to know other people’s sides of their lives and their brother’s/sister’s personalities with autism.”

John Kee, age 20

“Danny and I have an interesting trajectory in our relationship,” says John about his older brother, now 24.

During the first years of his life, “Danny was cognitively older than me...and I idolized him like a big brother.” Then John caught up with his brother cognitively (Danny plateaued at around the age of 6) and they became best friends. “Then, when I started to surpass him and become the ‘older brother,’ things became more difficult...and I had a bad reaction to it.”



The boys’ parents, Cecilia and Jim Kee, explained Danny’s autism to John at that point. “I was told Danny was special and that he can’t do all the things that I can do.” Still, John continued to struggle with jealousy and embarrassment over some of Danny’s behavior in public.

Fast track to maturity

Siblings of children on the spectrum tend to mature faster than their peers because of the challenges their families face. That was certainly the case for John at a young age when he had to realize how limited Danny was by his autism and that “it really was not fair for me to be angry with him all the time. I made a conscious effort to change my behavior and ... realized that if I wanted him to be treated inclusively by the world, it has to start in the family.”

He took responsibility for caring for Danny and parenting more than a younger brother should. He came to be referred to as “the little big brother,” a term he always has liked.

John notes that most of the support he received was from within his family. He did participate in a summer program for siblings of children with disabilities but never stayed connected with the other kids in that program. It was through his work as a camp counselor at the Mary Campbell Center that he found camaraderie with other siblings. He wishes he could have had that camaraderie as a regular part of his life.

Looking to the future

Having Danny in his life has changed his world view, says John. “He has made me so profoundly grateful for being able-bodied and able-minded because it’s something we take for granted so often.” This heartfelt conviction, coupled with his exposure to the special-needs population at the Mary Campbell Center, has prompted John to consider studying to become a neurologist after he graduates from Vassar College in 2019.

As an adult, Danny is working through POW&R, Autism Delaware’s adult vocational program. John knows that he is next in line to take care of care of his brother when his parents no longer can. His

family hasn't made a formal plan yet and he has expressed to his mom that he would like to do that before Danny goes into a group home.

John's commitment to Danny's long-term well-being has bumped up against the freedom and independence he has enjoyed being away at college, and he admits that it has been "really liberating to live without the limitation of autism in the household...I realize more now what it's like to live a normal life."

This taste of independence has made decisions about his and Danny's future "more complicated," he says. While he loves the freedom of living without autism, he also deeply loves his brother. "There are three people on this planet who Danny can look in the eye, and I'm one of them. Depriving him of that connection would be very hard."

Tabatha Brown Flowers, age 51

Tabatha is the caregiver for her younger brother Omar, 45, who is in the POW&R program. She also takes care of her wheelchair-bound mother Evelyn, who has Parkinson's disease, and her 4-year-old granddaughter, Ariyanna.

In addition to these responsibilities, she works full time as a para-educator and is pursuing a Master's degree in Special Education & Severe Disabilities.



"It's my platter," she says of this very full plate. "Welcome to it."

Tabatha's ability to juggle the care for three family members across three generations—as stressful as it often is—is rooted in a deep love. "It's my family and I love them," she says. "I'm going to do whatever I need to do to take care of them safely."

She comes by this devotion honestly, for her parents involved everyone in supporting Omar. As soon as he was diagnosed between the ages of 3 and 4, they all went in to therapy. Tabatha had sessions with the entire family and by herself.

Before Omar became verbal, Tabatha remembers her mom saying that children start to speak at different times and Omar needed more time. "I was encouraged to read aloud to him to help him with words."

When Tabatha felt challenged—such as when other kids would make fun of Omar or tease them—she was able to share her concerns with her parents. "Usually I had a few choice words for those people," she laughs.

The big sister

"Omar and I got along great," Tabatha says. "I really enjoyed being the big sister and as I got older, he went everywhere with me... He also protected me."

There were times, especially early on, when Tabatha felt Omar got all the attention. "It seemed like my parents were more concerned with him...I remember feeling left out sometimes and even upset when it seemed he was given more leeway on things."

Still, growing up she didn't feel like she was denied or missed out on anything. "My friends were great with Omar. They never looked at him differently and they treated him like he was their younger brother as well."

Tabatha only knew one other person who had a sibling with autism "and we were joined at the hip," she says. Today, she wishes that she lived closer to the rest of her family so that she could have more support to ease her caregiving responsibilities. Her busy schedule makes it difficult to find time to connect with others who are living with an adult with autism, let alone also caring for a parent and a young child.

Getting a life

Omar is relatively high functioning and good with routine, and helps as he can with the caregiving. But Tabatha feels that for him to remain in her home in that capacity "would suffocate Omar and keep him from having a life." She makes sure he gets out of the house and has learned that she doesn't have to go with him to every event—he can take Paratransit.

One of her greatest concerns is, who going to care for my brother with autism when I no longer can? She has been looking at group homes for him and/or considering whether he could live with his nephew when she is no longer able to care for him.

It is a question that siblings consider, no matter what their age.