

On September 8, 2014, Jewish Family & Children's Service (JF&CS) and Jewish Residential Services (JRS) presented a program exploring sibling perspectives on disabilities as part of a bi-monthly educational series entitled "AIM: Support for Families of Adults with Special Needs." The free program took place in a conference room at Jewish Family & Children's Service in Squirrel Hill. A light kosher meal was provided.

The format was a moderated panel discussion. Attendees had opportunities to ask questions and share comments. A summary of the discussion appears below.

*What was it like to grow up with a sibling with special needs?*

- Every family has its "stuff." I thought our family was "ordinary."
- Everything we did as a family was inclusive so the disability didn't stand out.
- I grew more protective of my sibling as we got older.
- I didn't want people to feel sorry for me on account of my having a sibling with a disability.
- I reacted violently when people used the word "retarded."
- There was a lot of laughter in our home. Having a sense of humor was important.
- Routines were very important.
- My friends were accepting; I guess they took their cues from me.
- I prepped my friends before introducing them to my sibling.

*Did you know other siblings of children with special needs when you were growing up?*

- No. I guess I could have reached out to siblings of my sibling's friends but I didn't, probably because I had friends of my own.

*How does sibling's disability continue to influence your life now that you are an adult?*

- I have a habit of rocking like my brother.
- I am aware of different kinds of communication.
- I am more empathic, compassionate and sensitive.
- I ended up in a helping profession, doing work that feels meaningful to me.
- I got genetic testing before having kids.
- My husband and I moved in with my parents and siblings so we can help out.
- I see similarities between my sister and me which helps me relate to her.
- I moved back to Pittsburgh when my parents died so I could be more involved in my sibling's care.
- My biggest fear is that someone will mistreat my brother because he is so vulnerable.
- I recognize the value of living in a community where people know my brother and look out for him.
- I understand what it means when people say "you do what you have to do."
- I don't take things for granted.
- I am patient and good at waiting for my turn.

*Have your experiences influenced your choice of mates?*

- Yes. My spouse “gets” my sibling and is supportive of our relationship, which is very important to me.
- Probably, because I married a special education teacher.
- Yes. I married the best friend of my typical sibling, so he already knew my family.

*Have you ever disagreed with your parents about your sibling’s care?*

- I used to advocate on my brother’s behalf. For example, I argued that he should be allowed to have a driver’s license.
- My sister really wanted to drive and my parents said she couldn’t so I took her to an empty parking lot and let her try it.
- Right now there’s a lively discussion about my sibling’s marriageability.

*To what extent will your relationship change in the future, e.g., when your parents can no longer be primary caregivers?*

- My other siblings and I have already begun taking on more responsibility.
- My parents have I have already discussed guardianship.
- My parents have always told me that I am not responsible for my brother, but I inherited their value of taking care of family.
- My parents have been taking care of my sibling for a long time. I want them to be able to relax and enjoy themselves.
- My parents have kept me in the loop so I have a good sense of what’s involved in my sibling’s care.
- My mom is extremely organized and documents everything which has made it easier for me to take on more responsibility.

*Do you ever feel a sense of guilt about being typical?*

- Not really, but it makes me sad that my sibling has to struggle so much.
- No, because I don’t think my sibling is unhappy.
- Yes, but my guilt comes from feeling like I am not doing enough to help my sibling.
- I don’t feel guilty because I believe we all have a purpose.

*Do you ever feel cheated that your sibling gets more attention than you do?*

- No, I am grateful I don’t need more help.
- No, I feel blessed to have my sibling.
- I recognize that my mom worked very hard to help my sibling but I don’t feel cheated because of that.

*Other comments*

- Mental illness poses unique challenges that can be especially hard for siblings to manage.
- ACHIEVA’s Family Trust Department is offering “Sib Shop” support groups for siblings.
- Support groups can be great for sharing resources but some people do not find them helpful.