

Social, Emotional and Educational Impacts on Siblings of Individuals with Disabilities

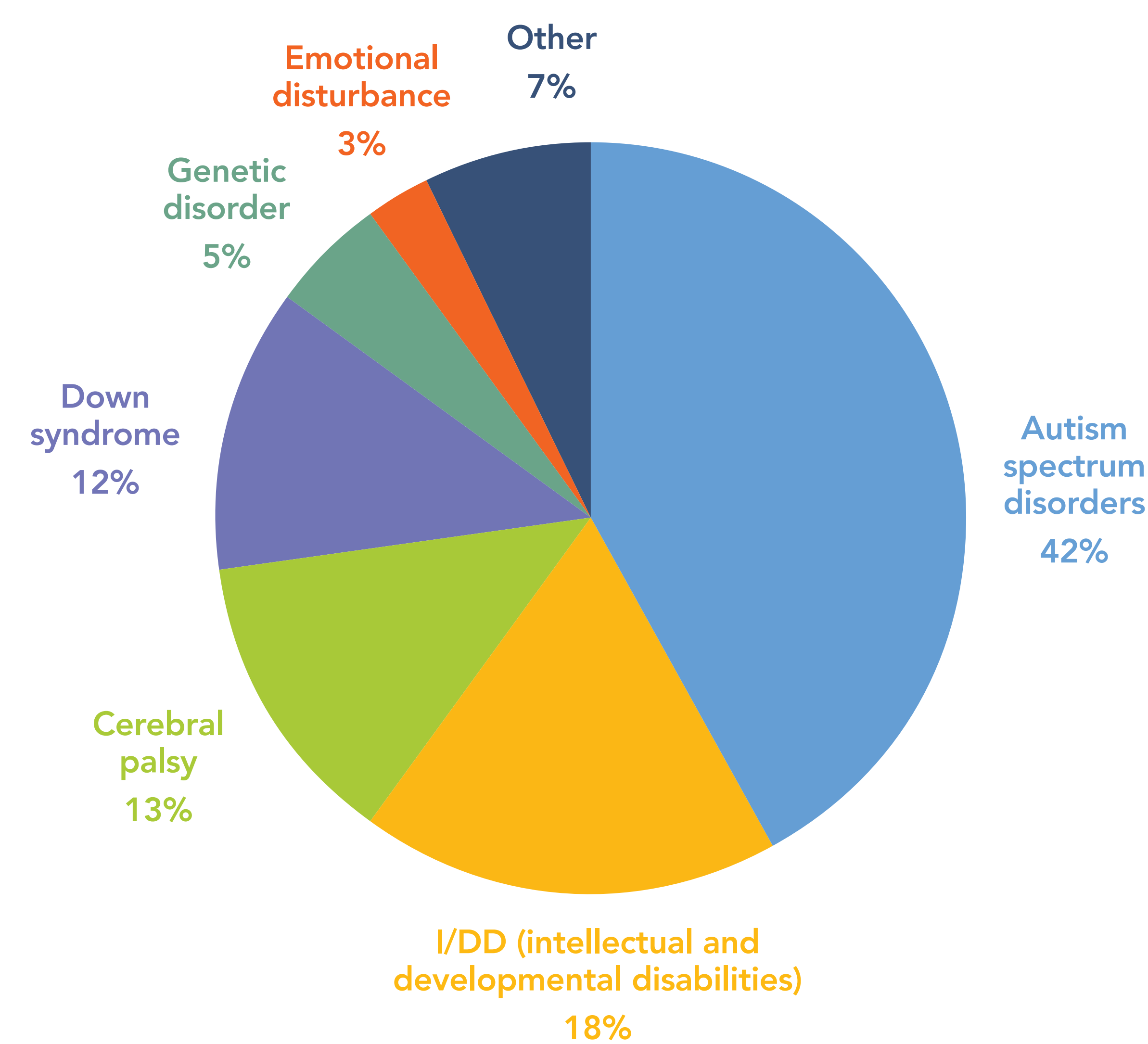
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Background

- An online survey was distributed to collect data on the experience of individuals raised with a sibling with a disability.
- The purpose of the survey was to collect data to better understand the experience of siblings of individuals with a disability, and to gain a more thorough understanding about how to better support families.
- The survey targeted young adults who grew up with a sibling with a disability, as the authors believe they are in the best position to reflect on their childhood and young adult experiences.
- The survey questions focused on the social, emotional and educational impacts of growing up with a sibling with a disability.

Participants

Primary Disability

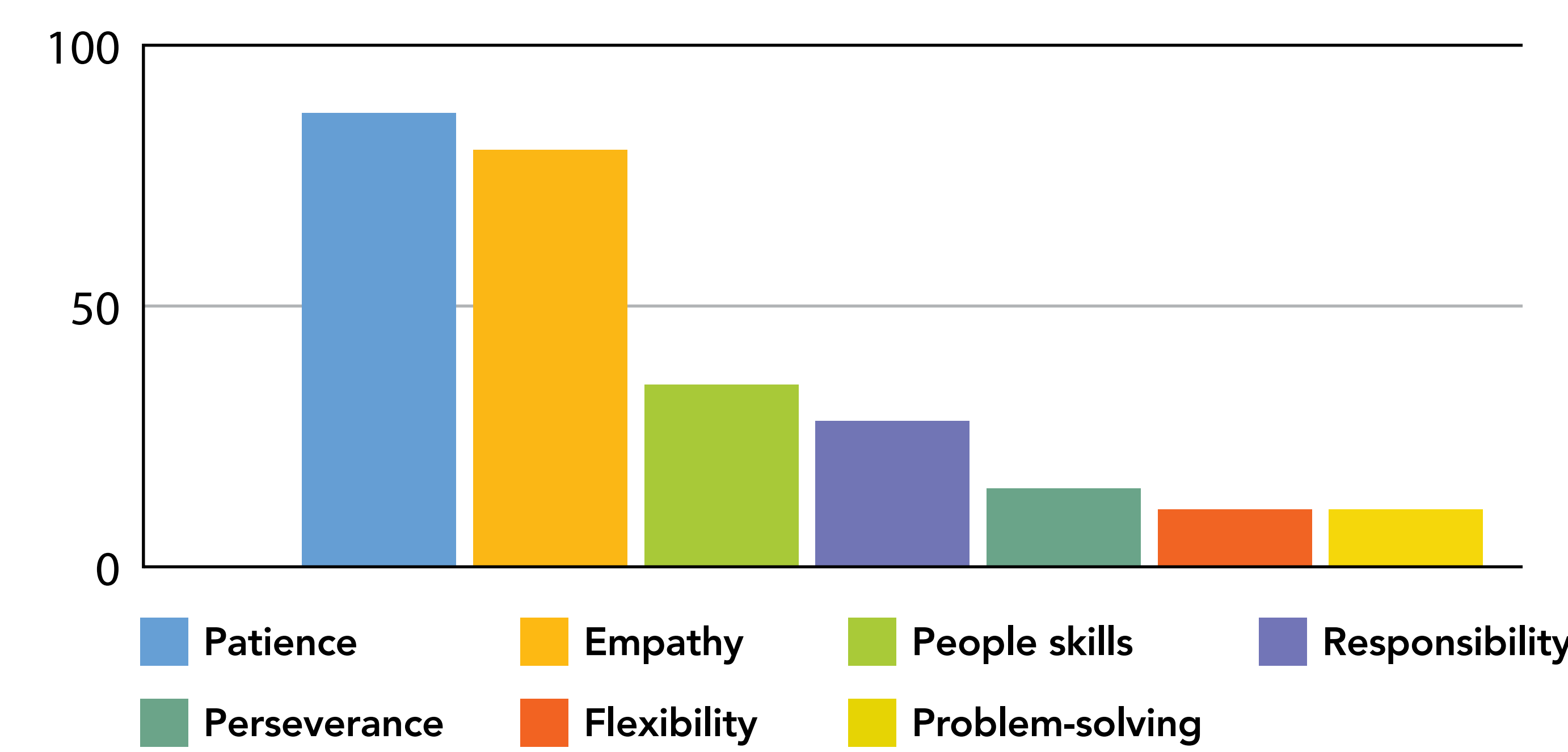


- The survey was completed by 204 unique participants. Participants resided in 31 U.S. states and four countries (England, Australia, Canada and Argentina).
- The majority of respondents (42 percent) were between the ages of 24 and 34. Individuals ages 18 to 24 accounted for 27 percent of respondents, individuals ages 35 to 44 made up 16 percent of respondents, six percent of respondents were under the age of 18, five percent were between 45 and 54 years old, and only three percent were over 55 years old.
- Only 11.27 percent of individuals identified their sibling's disability as "mild." The majority of participants (46.08 percent) categorized their sibling's disability as "severe," and 42.65 percent of respondents classified their sibling's disability as "moderate."
- A majority of respondents (57 percent) identified themselves as older than their sibling with a disability, while 40 percent identified themselves as younger than their sibling with a disability; 3 percent of respondents were the same age as their sibling.

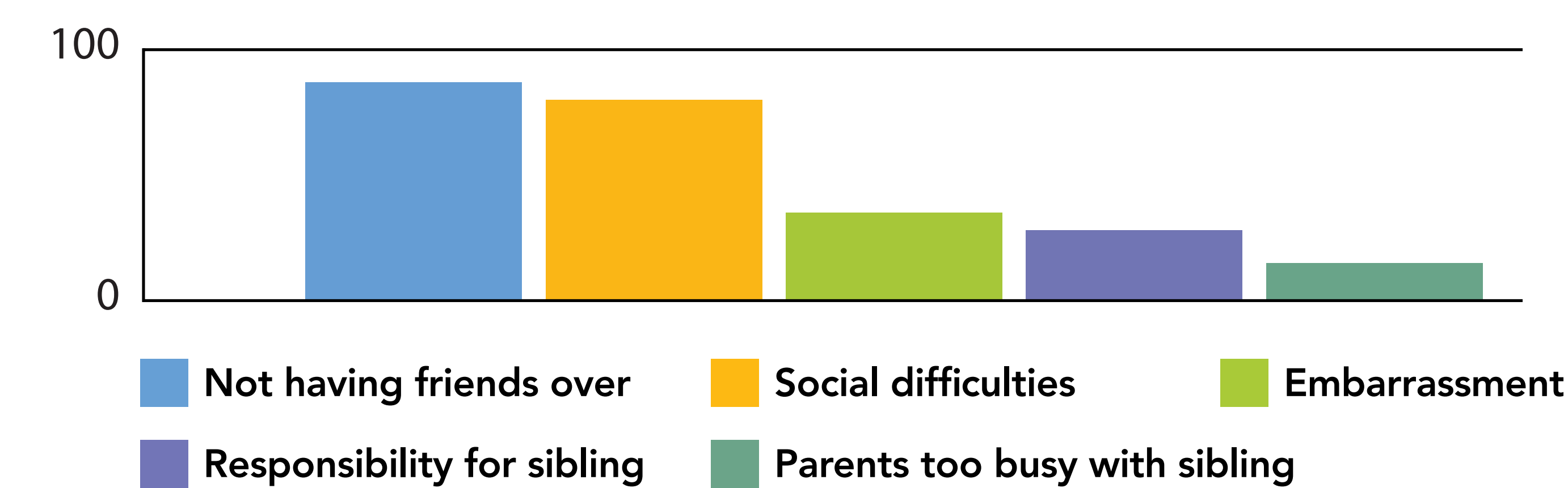
Survey Results—Social, Emotional and Family Impacts

The following graphs compile information received from individuals who completed the survey. In each graph, the Y axis represents the number of respondents who identified with each situation listed on the X axis.

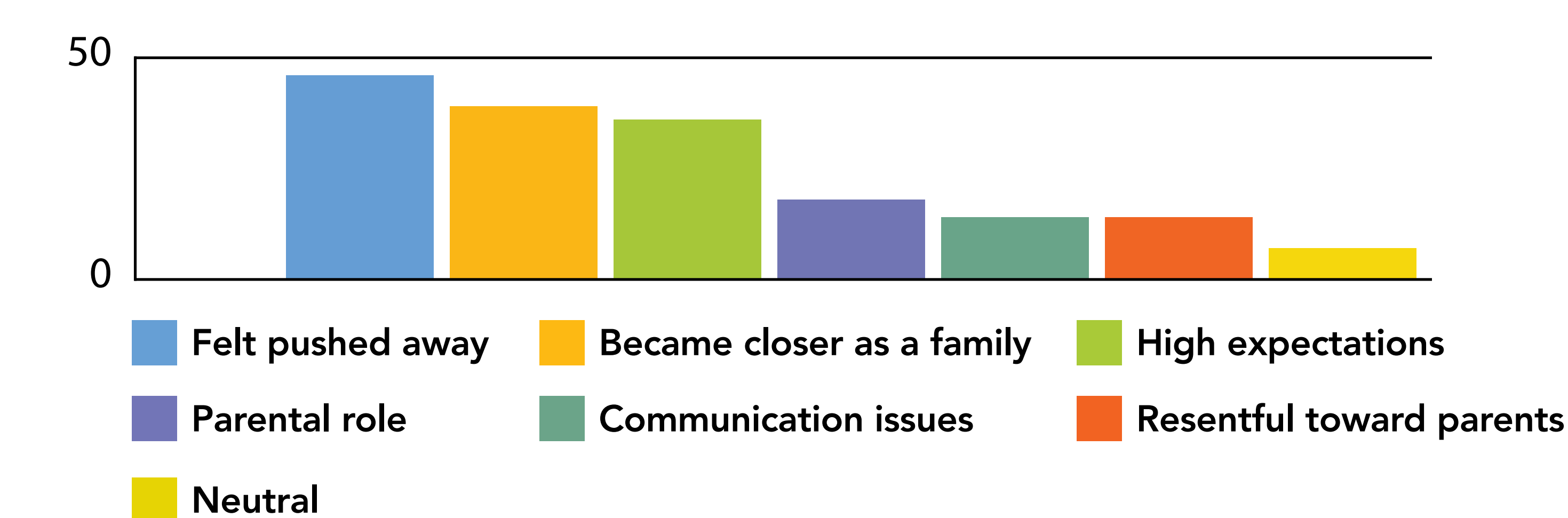
Skills Learned



Negative Impacts



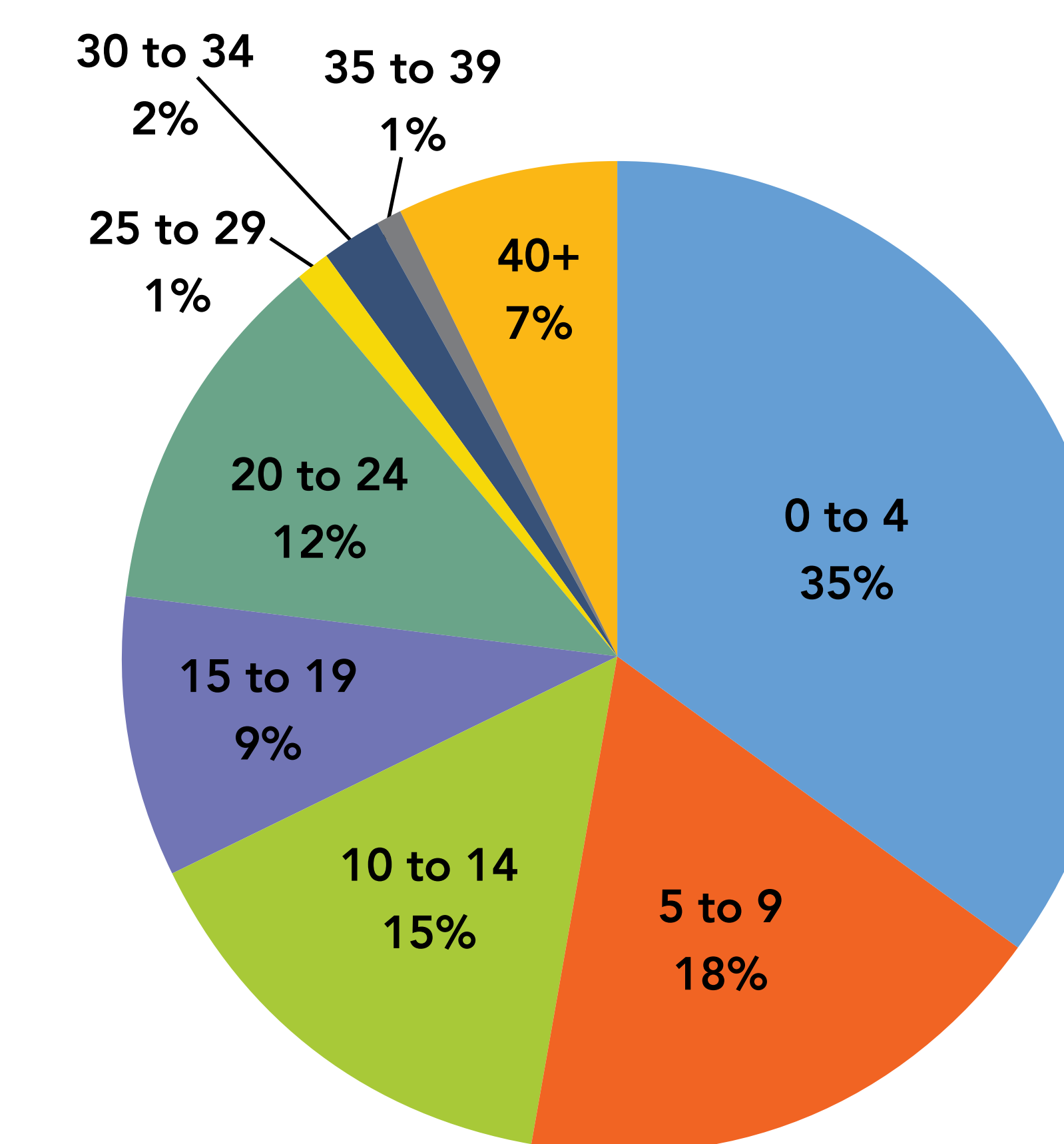
Impact on Parental Relationship



Survey Results—Educational Impacts

- The majority of individuals indicated their sibling attended a public separate day school (28.6 percent), while 20.2 percent went to the same school as their sibling. Other individuals never attended the same school as their sibling due to a large age gap (23.2 percent).
- 74 percent of individuals were absent fewer than 10 days per school year.
- 91.1 percent of individuals never had to miss school to help care for their sibling.
- 89 percent of individuals reported a high school grade point average of 3.0 or higher.
- 86.3 percent of individuals participated in school-related extracurricular activities in a variety of areas such as sports, music and clubs.

Hours Caring for Sibling Per Week



Participant Responses

- "I'm closer to [my siblings] than I am to anyone else in my life. Since I'm older and helped raise them, I honestly think of them more as my children than my siblings, and I think they similarly regard me as a caretaker, to the extent that my sister experienced separation anxiety when I moved away for school. I'm about to move back home to be closer to them. I plan to become their sole caregiver when my mom is no longer able to fulfill that role."
- "Having friends over could be tricky because my brother had frequent meltdowns. I had to be a very motivated kid and advocate for what I wanted academically and after school to my parents because they were busy with him."
- "I feel like I definitely developed more empathy for people in difficult situations like mine. It helped shaped my personality. It also made me more focused on my goals and my future, because my brother was a big part of my future."

Discussion

This survey sought to gain perspective on the social, emotional and educational impacts of growing up with a sibling with a disability. The survey's authors found most respondents did not report negative educational impacts as a result of having a sibling with a disability. Most individuals surveyed identified themselves as students with higher-than-average grades, regular attendance at school, and participation in a wide range of extracurricular activities.

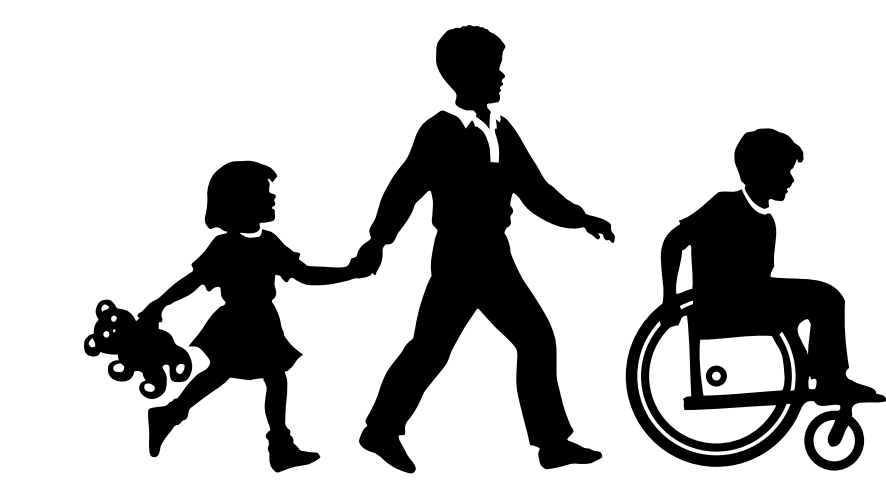
Participants were asked what skills they learned (if any) from growing up with a sibling with a disability. A large number of individuals indicated they learned the skills of patience and empathy. Regarding the negative impacts, many respondents reported they often could not have friends over to their family homes during their childhood. Other social difficulties reported varied from not being able to go to social activities due to taking care of their sibling, to having to deal with other children trying to tease their sibling. Interestingly, respondents reported both positive and negative impacts on their relationship with their parent(s). The most commonly reported parental impact was that the individual felt pushed away by their parent(s), while the next-most reported impact was that the individual felt their experience with their sibling made them closer as a family. Many individuals also reported they felt there were higher expectations placed on them due to their sibling's disability. This sentiment typically came either from things directly stated by their parents or from their internal beliefs.

Survey Limitations

- The authors failed to collect data regarding the respondents' race, ethnicity, gender and socio-economic status.

Gratitude

- The authors would like to express their gratitude to Don Meyer, director of the Sibling Support Project, and to all respondents who completed their online survey.



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