



Understanding the needs of siblings of individuals with disabilities: Their perspectives

A Research Report for Families and Community Partners

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Introduction

Sibling relationships have been described as “some of the most intimate, enduring, troubling, and conflictual relationships that we may experience in our lives” (Hindle, 2018, p. 4). The sibling relationship can be further muddled by the needs of the sibling. For example, the sibling without disabilities may assume caretaking roles for their sibling with disabilities, which in turn impacts their relationship. As the number of individuals with disabilities continues to grow, so does the number of siblings that may assume caretaking roles (Lee & Burke, 2018). The added responsibility may present physical, financial, and emotional challenges as the sibling without disabilities also may need to cope with other aging family members and finding services for their sibling with a disability (Lee & Burke, 2018).

Adult siblings of individual with disabilities have reported benefits and challenges. Benefits include positive personal characteristics such as greater empathy, feelings of compassion, positive impacts on their career choices, and stronger sibling relationships (Chase & McGill, 2019). Challenges include that some siblings report having to mature at early ages and fulfilling caregiving roles during childhood

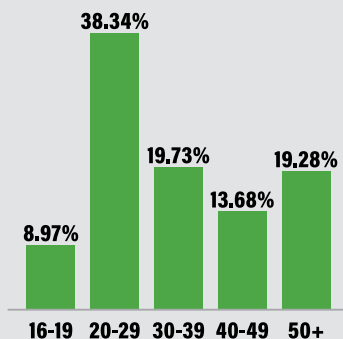


(Chase & McGill, 2019). Further, some siblings of individuals with disabilities report feeling neglected by their parents, and lacking support from other family members or from people outside the family (Moyson & Roeyers, 2012). Some siblings additionally report experiencing stress due to stigma about disability in the community (Hanvey et al., 2022).

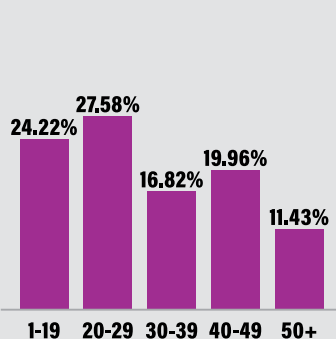
Supports may be helpful for **all** siblings. Supports can be characterized as (a) individual supports or for one’s self (Moyson & Roeyers, 2012); (b) family supports or for the family as a whole (Dervishalia & Murati, 2014); and (c) systematic supports or supports to educate the community or society (Dervishaliai & Murari, 2014).

Participant Demographics:

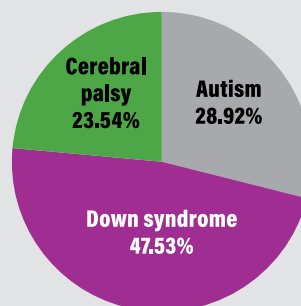
Participant Age



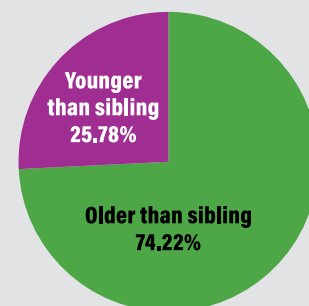
Sibling Age



Type of Disability of the Sibling



Birth Order of Participants



The purpose of this research was to explore and analyze the perspectives of adult siblings without disabilities on their experiences while growing up with siblings with disabilities.

Who Participated

This report is based on the perspectives of 446 adult siblings of individuals with autism, cerebral palsy, and Down syndrome. Participants (adults without disabilities) were predominantly White (91.03%), female (78.70%), and between the ages of 20-29 (38.34%). Most of the participants were college graduates (64.13%) and full-time employees (59.87%). Almost half were married (46.64%), lived with their spouse or significant other (52.69%), and did not have children (61.66%). Close to three-quarters of the participants (74.22%) were the older siblings of individuals with autism (28.92%), cerebral palsy (23.54%), and/or Down syndrome (47.53%). Most of the siblings with disabilities were male (61.66%), and living in their family home with their parents or another relative (54.93%). Most of the participants' (72.56%) indicated that their parents had 'moderate to excellent' abilities to take care of their sibling with disabilities.

Research Design and Analysis

A cross-sectional survey was developed by 10 individuals, consisting of: (a) siblings of individuals with disabilities; (b) experts in the field of sibling research; and (c) the National Sibling Research Consortium. The purpose of the survey

was to collect information on siblings' perspectives on the need for supports. A total of 16 demographic questions were included and one open-ended response question asking, "What would have helped you growing up as a sibling of a child with disabilities?" Participants were recruited through websites such as, the Association of University Centers on Disability, the Vanderbilt Kennedy Center, and The Arc's dissemination networks. The Arc also included information on the study in InSight, their national newsletter (sent to 90,000+ subscribers). The announcement was sent to the Sibnet Network, state Developmental Disability Networks, and newsletters. Thematic analysis was used to code open-ended responses. Univariate statistics were used to compare the themes to participants' demographic information.

Findings and Recommendations

Four themes were identified from participants' responses. Although over three quarters of the siblings without disabilities (81.39%) reported that there was a need for support during their childhoods, some participants (18.61%) indicated no supports were needed. From the participants who indicated the need for supports, 36.49% mentioned wanting 'supports for themselves' (theme 1). Within this theme, participants requested that it would have been helpful to: (a) know other siblings of individuals with disabilities (43.21%); (b) receive acknowledgment from others about the potential impact of having a sibling with disabilities (16.05%); (c) have less responsibility in the care for their sibling (12.96%); (d) have someone guide their relationship with their sibling (16.05%); and (e) receive counseling services to help them navigate having a sibling with disabilities (11.73%). For example, a sister to a 27-year-old with autism, reported wanting, "To know that

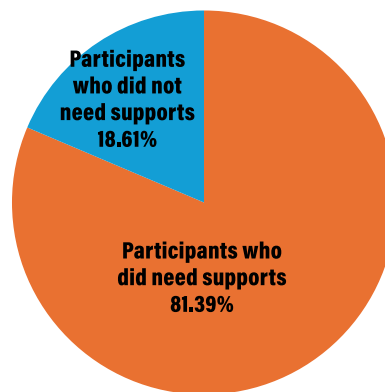
it wasn't something to be ashamed of, to know that I was not alone, to meet other siblings, to meet other people with disabilities with behavioral issues.”

Over a quarter of the siblings without disabilities (29.95%) indicated that it would have been helpful having ‘disability awareness’ (theme 2). Specifically, they described: (a) wanting knowledge on the sibling’s type of disability (53.38%); (b) wanting society to be more knowledgeable about and accepting of people with disabilities (33.08%); and (c) having awareness of disability specific resources (13.53%). A sister to a 14-year old with Down syndrome, provided reported wanting to “having more community acceptance and understanding. Having people look beyond the Down syndrome and see my sister as a person first, not her diagnosis. Also have more information on what it meant to have a sister with Down syndrome.”

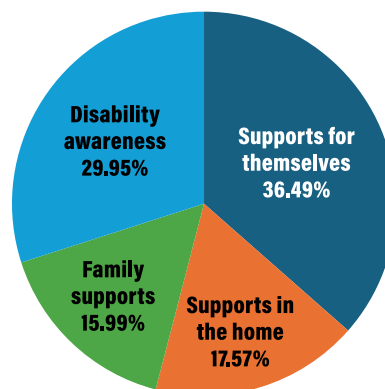
Another view shared by 17.57% of siblings without disabilities, was that it would have been helpful having ‘supports in the home’ (theme 3). Participants who shared this perspective reported wanting to: (a) receive attention from parents or other family members (58.97%), (b) have another sibling without disabilities (21.79%), and (c) have a stable home environment (19.23%). Participants stated wanting, “more patience; some quality alone time with my mother; older brother, sister.” (Participant 2409, a sister to a 4-year-old with Down syndrome, regarding attention from parents or other family members). They also noted, “Having another sibling about my age that understood what it was like to have a sibling with disabilities, and what we face every day...” (Participants 481, a sister to a 19-year-old with DS, regarding having another sibling without disabilities). Lastly, participants reported wanting, “Having a father there. I feel a father figure would have helped out alot [a lot] with the boys especially. My mom has done the absolute best that she can be shes [she is] only one person and she can't hold every position” (Participant 2554, a sister to a 15-year-old with ASD, regarding wanting a stable home environment).

Although less frequent, 15.99% of participants reported the need for ‘family supports’ (theme 4); particularly, for their sibling with disabilities and family, overall. The theme of ‘family supports’ included supports from the school and community (66.20%), and respite care services (33.80%). A sister to a 48-year-old with cerebral palsy, reported: “respite care for my parents would have helped all of us. Also, having more services, educational, medical, physical, speech and occupational therapy and teachers who

Supports Needed Participants Perspective



Types of Supports Needed Siblings Perspective



actually knew what they were doing would have made all the difference.”

Having a sibling with a disability has a significant impact on the sibling without disabilities (Moyson & Roeyers, 2012). The sibling relationship is lifelong. Thus, supports should be given to siblings without disabilities. Indeed, there is a need for supports to be in place to not only for the sibling with disabilities but also for the siblings without disabilities (Barr & McLeod, 2010; Chase & McGill, 2019). Sibling supports may increase the ability of siblings without disabilities to advocate for and provide caregiving to their siblings with disabilities.

Call to Action

Based on the perspectives of 446 siblings of individuals with disabilities, their needs have been under-supported. To support siblings, changes are needed to provide and create opportunities for: (a) sibling support groups, (b) disability awareness, (c) provide additional supports in the home

environment, such as respite care and family education; and (d) have resources available for the sibling without disabilities, such as sibling groups, counseling, among others.

Consider the following steps in a call to action to:

- ❑ **Sibling groups and counseling services** tailored to siblings of individuals with disabilities, and on how to improve their relationship with their sibling. This will help siblings learn from others who have similar experiences and provide them with the acknowledgment that they are not alone.
- ❑ **Disability organizations** to consider resources specially made for siblings of individuals with disabilities across the lifespan, so that young children and teenagers can have access to such resources. These will help individuals with disabilities better acclimate into society, as well as teaching siblings how to support their siblings in potentially overwhelming environments.
- ❑ **Disability organizations and community services**, to have resources that will help the community and society to become more knowledgeable and responsive to the unique needs of individuals with disabilities, and their families. Only, by doing so, will society be better prepared to help deal with the needs of siblings, of individuals with disabilities, and specifically, of those with potential challenging behaviors.
- ❑ **Respite care**, to increase the possibility of services, hours, and providers. This will allow for families to have time to support and give attention to all of their offspring. Additionally, siblings will face less of the responsibility in the care of their sibling, reducing stress and feelings of resentment.
- ❑ **Schools and communities**, to increase their efforts and provide opportunities for siblings with disabilities to grow in their abilities and participate across the various community and school activities. By providing supports like these, individuals with disabilities will be supported at a younger to engage in community activities with their siblings and families.

By providing more, cumulative supports to siblings without disabilities, the hope is that they will be prepared for the lifelong responsibilities that come with being a sibling to an individual with disabilities. Beyond that, the hope is also that these siblings will receive the supports needed to allow them to express and deal with their emotions of having a sibling with disabilities throughout childhood and teenage years.

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