



The Experiences of Siblings of People with IDD during the COVID-19 Pandemic

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The Experiences of Adult Siblings of People with Intellectual and Developmental Disabilities during the COVID-19 Pandemic: An Update

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This past year has had an enormous impact on people with intellectual/developmental disabilities (IDD), as well as their families. What many don't realize is that this is not only a concern for parents, but it also weighs heavily on their brothers and sisters, the people who have the longest relationship with their loved one with IDD. It is important that we understand the experiences of siblings of people with IDD during the COVID-19 pandemic so we can not only improve supports for people with IDD, but also know how to effectively support their families during this challenging time.

What did we learn about siblings' experiences at the start of the pandemic?

Between May and July of 2020, our team of [siblings](#) and [researchers](#) worked together to better understand the experience of adult siblings through an online survey shared across Canada. The survey explored the specific concerns of siblings, their emotions, and the resources that they have found helpful throughout the pandemic. We heard from 91 siblings, the majority of whom were women from Ontario, between the ages of 20 and 39 years old. Findings showed that the majority of siblings were worried about the health and wellbeing of their brother or sister with IDD, with the most common concern focused on the disruption of routines and activities. The three top emotions siblings identified feeling during this stage of the pandemic were worry about the future, stress, and guilt. During this time, siblings benefitted from their relationships with others (including connecting with other siblings in similar situations), and having financial, information, practical, and emotional supports available for their brother or sister with IDD. For more detail, you can find an [infographic](#) about the study or read the full research paper [here](#).

How have siblings' experiences changed over time during the pandemic?

In late fall of 2020, we sent a follow-up survey to further understand the sibling experience and to see how things had changed six months later. A total of 60 of the 91 siblings from the first survey responded, and this subgroup was similar demographically to the original group.

In many ways, what we heard at this second time point was similar to what was described the first time. Most siblings reported minimal changes with respect to their caregiving roles. The majority (70%) of siblings during Time 2 reported that they were still providing support to their brother or sister with IDD and most (90%) were still concerned about the health and wellbeing of their loved one. The only difference we found between these time points pertained to the emotions siblings were experiencing. Unlike during Time 1, siblings identified sadness within the top 3 emotions. This sadness mostly concerned the loneliness and the losses that their brother or sister with IDD was experiencing as a direct consequence of the COVID-19 pandemic. For instance, siblings spoke of the impact that losing structured activities and the connections they provided had on their brothers and sisters with IDD: "My brother is missing out on so much that gives him meaning."

Compounded worry: Concerns about health of their parents and brother/sister with IDD

Several siblings shared their concerns for their parents' health – specifically their parents' mental health:

"My parents' mental health and coping skills have decreased as they experience frequent low moods, feeling of no hope for the future, worry/over worry about the virus."

These concerns similarly extended to their brother and sister with IDD, however, many siblings expressed worry about their brother's/sister's declining mental *and* physical health. Inactivity was a common contributor to the decline in wellbeing: "He's less active now as he's not forced to go anywhere so he doesn't move. He's gained weight." Another sibling similarly described how her brother's inactivity was impacting his mental health: "My brother is very anxious by nature...and his own lack of activity has really escalated his anxiety level."

Supports for people with IDD during the COVID-19 pandemic

Siblings were asked about the services, supports, and/or activities that their brother and sister with IDD were using during the COVID-19 pandemic. More than half (55%) of their brothers and sisters with IDD had attended virtual services, supports, and activities. However, 93% of siblings reported that their brother or sister with IDD preferred in-person, as compared to virtual, supports and activities: "My sister is a very loving, affectionate and social person. She appreciates meaningful physical human interaction." Some siblings also described challenges their brother or sisters experienced around virtual engagement:

“She relies on body language and familiar people/ routines to communicate her needs and interests”.

“He needs a lot of encouragement to participate and isn't able to get that when he's on Zoom. He fades into the background and doesn't get anything out of virtual events.”

Future planning

Siblings were asked if the COVID-19 pandemic encouraged them to engage in conversations with their family around future planning for their brother or sister with IDD, in which half of siblings (50%) responded “yes”, but this was not necessarily as a direct result of the pandemic. In several cases, siblings indicated that they were having these conversations prior to the pandemic, but the pandemic changed the nature, tone, and urgency around this crucial but difficult conversation. Siblings also highlighted how accessing supports to facilitate future planning discussions proved to be difficult:

“This has been a frustrating experience as we get different, conflicting information from different supports. We are unsure of what supports are actually available and what steps we need to take in order to access them.”

Supports for siblings of people with IDD during the pandemic

When participants were asked how they could be better supported as a sibling of someone with IDD during the COVID-19 pandemic, many explained how the impact the pandemic was having on their brother or sister with IDD was, in turn, impacting their own mental health. Several siblings noted the guilt they felt, calling it “awful,” and expressing the need for sibling-specific “mental health tools to help cope with guilt, find acceptance and hope.”

What do service providers and policy makers need to know?

Get to know my brother/sister with IDD

Siblings implored service providers and policy makers to get to know their brother or sister with IDD to be better able to understand their needs. One sibling wrote, “He is smart and when he is acting up, he isn’t being manipulative, he is usually just anxious about something.” Siblings also noted that their brothers and sisters need to be seen in a holistic manner, recognizing their strengths along with their support needs: “Treat my brother with respect and use humor. He can read people much better than you realize.”

Many siblings indicated that policy makers need to be aware that their brothers and sisters are not receiving adequate supports and that families need support navigating the service system:

“They need to invest in proper supports for adults with DD rather than just throwing money to families and having them find things on their own....”

“...my brother and people with disabilities deserve better than they are getting. We still have a long ways to go. Real change needs to happen.”

Without such change, siblings noted their brothers and sisters will continue to experience discrimination in a society that seemingly disregards their needs and ultimately disvalues their worth:

“Their... quality of life and lower life expectancy is because they've been left behind and are always last on the list, but they could thrive so much more with a truly caring investment in a society that lifts them up and invests in their inclusion and success.”

Get to know me

Siblings highlighted the important role families play in supporting their brother or sister with IDD and asked service providers to take the time to consult with them and work together to improve the quality of care for people with IDD:

“Family holds the history and story of their sib, it is vital that service providers listen to the stories of our sibs. Stories of folks with IDD notoriously get lost in systems.”

“Policy makers need to recognize that siblings are there to help with the decision-making, and to fill in the knowledge gaps for our brothers and sisters so that they are treated fairly and have the opportunities to make the most of their lives.”

Recognizing the importance and value of including family in the care of people with IDD, siblings also wanted policy makers and service providers to know that they “count too” and feel as though they “often fall through the cracks.”

CONCLUSION

The impact of the COVID-19 pandemic continues to weigh heavily on families of people with IDD. As the ebb and flow of public health restrictions continues to disrupt the routines and everyday lives of people with IDD, siblings are experiencing high levels of stress, worry, and sadness. While resources are clearly needed to support people with IDD during the pandemic, the needs of siblings are often overlooked:

“... [we are] potentially the longest-lasting relationship in our brother/sister's lives and we need to be supported from the beginning, and not considered an afterthought.”

To read more about The Sibling Collaborative, go to www.sibcollab.ca and to read more about strategies during COVID-19 for people with developmental disabilities and their families, go to www.hcarddcovid.com/info.

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