

# **Understanding the Sibling Experience**

## **Sibling Needs Assessment Survey 2017**

**Prepared by the Sibling Collaborative**  
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## **Acknowledgments**

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## Introduction

A combination of better medical care, good lives in the community and other factors have led to longer life expectancies for individuals with developmental disabilities (“DD”) and many are now outliving their parents who have taken care of them over their lifetime (Ouellette-Kuntz & Martin, 2014). As a result, once parents are no longer able to provide the same level of support or care, the caregiver role often transitions to the sibling(s) of the individual with a DD. In many cases, this transition is often made alone – without support or adequate resources – and generates considerable stress.

Our brothers and sisters with a DD have their own life journey, which for many includes health obstacles, such as reduced mobility, medical procedures and cognitive challenges. Perhaps more challenging, however, is the social isolation and exclusion from society that can be faced. We acknowledge the great strength that our brothers and sisters possess as well as our genuine pride in walking alongside them throughout their lives.

We also acknowledge our parents for their grit and determination to do the absolute best for our brothers and sisters with a DD with the resources they have, or had, available to them. Despite experiences that have, at times, been isolated and lonely ones, our parents – like our brothers and sisters – have shown both strength and courage.

As siblings, we have the longest-lived relationship with our brothers and sisters (Cicirelli, 1995). We comprehend first-hand the struggles and the joys of this family life journey. Often, we, the ‘typical’ sibling, are understandably forgotten in the conversation, given the many other pressing issues to be discussed and managed, including medical care, personal support or creating meaningful opportunities.

Because siblings are likely to be the most constant companion in the lifelong journey of an individual with a DD, ensuring the long-term wellbeing of individuals with a DD requires identifying, considering and supporting the changing needs and challenges of their siblings over time. This study was created to better understand the typical sibling in relation to their own life, the life of their brother or sister with a DD<sup>1</sup> and their family at large. In doing so, we believe that we can better support siblings. And when siblings are supported, the entire family is strengthened.

Each sibling pair has their own unique story of how their relationship has evolved to arrive at where it is today. The following are a few glimpses into the stories of the authors of this report.

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<sup>1</sup> Although we often reference “a brother or sister with a DD” throughout this report, we recognize that some individuals are supporting two or more siblings with a DD.

### Eric's Story

*Sitting from his work desk Eric received a call from his distressed mother exclaiming "I just can't do it anymore". She was referring to caring for his sister, with a DD, 31 years old at the time. Eric had a decision to make – continue to stay arm's length from his family, or jump in and play the role of a loving brother and loving son that he knew he could be. This started Eric's journey in supporting families with a loved one with a DD (including his own), through personal coaching and educating.*

### Helen's Story

*All her life Helen knew that one day she would be responsible for her brother's care. When that day arrived, it was early, unexpected and fast. The shock of suddenly becoming a caregiver still runs through her. There are moments when she remembers a time when she could go away for the weekend without planning it or when she didn't have the nag of constant worry. It has been so far a difficult journey but she is very proud of how her brother has thrived with her care and how their relationship has grown.*

### Becky's Story

*Becky has spent the last seven years championing broad systems change through building community-based, non-traditional solutions to issues of isolation and vulnerability, both through her long-time work with P4P and as the sibling of an adult brother with Asperger's Syndrome. Becky has a close relationship with her brother and – together with her sister and parents – they navigate the challenges and opportunities of creating a meaningful life, secure future and strong family.*

## **The Sibling Collaborative**

The Sibling Collaborative is a partnership of adults with a brother or sister with a DD who have come together with the **purpose: To Connect Siblings and Strengthen Families**. The Sibling Collaborative has a core set of **values** that guides our work:

- **Realizing Change with Compassion:** We take action with the critical input and consideration of our brothers and sisters with a DD and our families.
- **Mutual Respect:** We give people agency over their own lives, with consideration for all those involved.
- **Collective Solutions:** We find a way forward by learning, working and co-creating together.
- **Unlocking Potential:** We hold a big and bold vision for our brothers and sisters as well as our families. Our intrinsic creativity and resourcefulness knows no limit.

## The Sibling Needs Assessment Survey

The Sibling Collaborative believes that individuals supporting a brother or sister with a DD can, over their lifetime, experience stress in their roles. This stress is compounded by a lack of helpful tools, resources and information to guide, inform and support them. To test this and other related assumptions, the Sibling Collaborative launched an online survey in the fall of 2017.

The primary objective of the Sibling Needs Assessment Survey (“sibling survey”) was to gain a deeper understanding of individuals with a brother or sister with a DD, specifically the challenges they face in supporting their brother or sister with a DD; the relevant areas in which they would appreciate tools, resources and information; as well as how and in what ways they would like to receive the identified materials. The Sibling Collaborative intends to use the survey responses and findings to advocate for the development and distribution of resources that adult siblings both need and desire, along with several other recommendations outlined later in this report.

Our survey, which targeted adults (20 years of age or older) residing in Canada with a brother or sister with a DD, received a total of 360 responses. The DD included a broad range of conditions that affect a person's ability to learn and usually last throughout his or her lifetime. A few examples of a DD might include, but are not limited to, autism spectrum disorders, Down syndrome or Fragile X syndrome.

The sibling survey was open for six weeks. The survey link was made available to siblings primarily through word of mouth and social media channels. It was also shared through the P4P, PLAN and CLO e-newsletters.

This report, “Understanding the Sibling Experience”, outlines the key findings from the sibling survey and, based on these, puts forward several recommendations for moving forward.

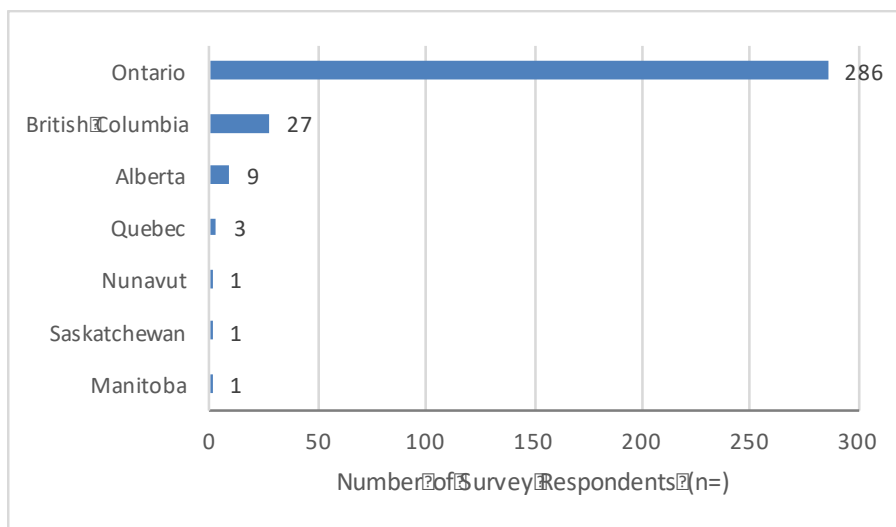
## Key Findings of the Sibling Survey

The following outlines the key results and findings of the sibling survey.

### Representativeness of Survey

360 adults (20 years of age or older) with a brother or sister with a DD completed the sibling survey. While the survey was targeted to those living anywhere in Canada, the vast majority of respondents who revealed their province of residence lived in Ontario (87.2%, n=286).<sup>2</sup>

**Figure 1. Provinces Where Sibling Survey Respondents Live**



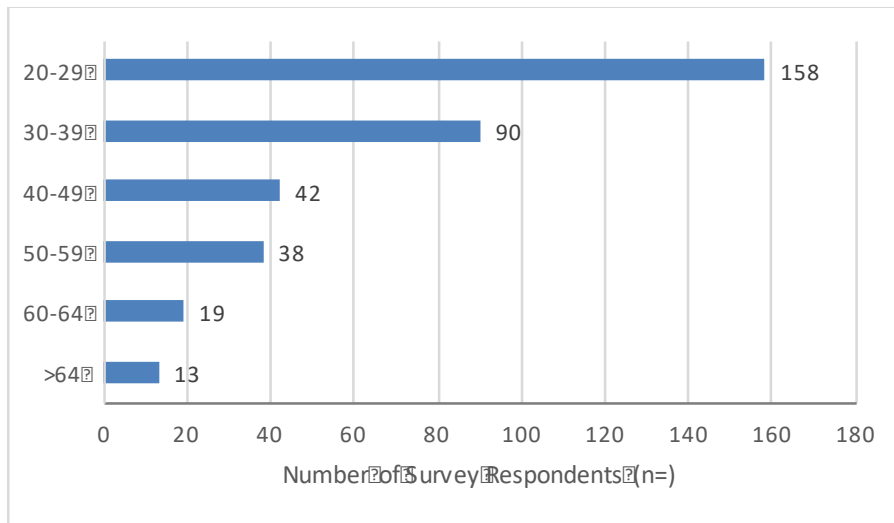
The most responses came from individuals residing in the following 12 cities: Toronto (n=74); Ottawa (n=27); Oakville (n=13); Mississauga (n=11); Markham (n=11); Vancouver (n=9); Kitchener (n=8); London (n=8); Whitby (n=7); Windsor (n=6); Burlington (n=6); and St. Catharines (n=5).

The greatest percentage of survey respondents fell in the age category of 20 to 29 years old (43.9%, n=158), followed by individuals between the ages of 30 and 39 years old (25.0%, n=90).

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<sup>2</sup> Of the 360 survey respondents, 30 did not indicate their province of residence and two lived outside Canada.

**Figure 2. Age Categories of Sibling Survey Respondents**



**Current Services and Supports**

A range of supports were offered as options in response to the question, “What kinds of supports does your brother(s) or sister(s) with a developmental disability receive from the disability organization to which they belong?” The most common current service listed was community involvement (61.7%, n=182).

**Figure 3. Services and Supports Currently Received by Brothers and Sisters with a DD**

<b>ANSWER CHOICES</b>	<b>Percentage<sup>3</sup></b>	<b>n=</b>
Community participation supports (e.g., volunteering)	61.7%	182
Day program	44.4%	131
Caregiver respite	33.9%	100
Person-directed planning	30.2%	89
Employment support	25.4%	75
Residential supports	25.4%	75
Professional and specialized services	23.4%	69
Other (please specify)	13.6%	40

<sup>3</sup> Expressed as a percentage of the 295 responses provided to the question on current services and supports.



## **Living Arrangements of Brothers and Sisters with a DD**

The [2016 Statistics Canada, Census of Population](#) revealed that 34.7% of young adults (20-32 years old) were living with their parents. The sibling survey found that, overall, 63% of brothers and sisters with a DD were living with their parents. At 85.6%, this rate was highest for the youngest age category of respondents (20-29 years old).<sup>4</sup>

We saw a gradual decline in siblings living with parents as the age category of the respondent increased. Among respondents aged 50-59 years and 60+ years, 82.3% and 92.9% of the brothers or sisters with a DD, respectively, were no longer living with their parents. It is also worth noting that as respondents aged, there was an increase in the number living with their brother or sister with a DD.

**Figure 4. Living Arrangements of Brothers and Sisters with a DD by Age Categories of Siblings**

	<b>20-29 years (n=146)<sup>5</sup></b>	<b>30-39 years (n=81)</b>	<b>40-49 years (n=41)</b>	<b>50-59 years (n=37)</b>	<b>60+ years (n=29)</b>
<b>Parents</b>	85.6% (n=125)	63% (n=51)	58.5% (n=24)	16.2% (n=6)	6.9% (n=2)
<b>You (Sibling)</b>	7.5% (n=11)	6.2% (n=5)	9.8% (n=4)	24.3% (n=9)	17.2% (n=5)
<b>Alone</b>	5.5% (n=8)	7.4% (n=6)	12.2% (n=5)	16.2%(n=6)	17.2% (n=5)
<b>Group Home</b>	5.5% (n=8)	11.1% (n=9)	7.3% (n=3)	10.8% (n=4)	24.1% (n=7)
<b>Other<sup>6</sup></b>	6.2% (n=9)	12.3% (n=10)	12.2% (n=5)	32.4% (n=12)	34.5% (n=10)

## **Intensity of Support – Now and In the Future**

Siblings were asked to rate (on a scale of 1 to 10) the intensity of the support they provide to their brother or sister with a DD. Siblings in older age categories rated their level of support as more intense.

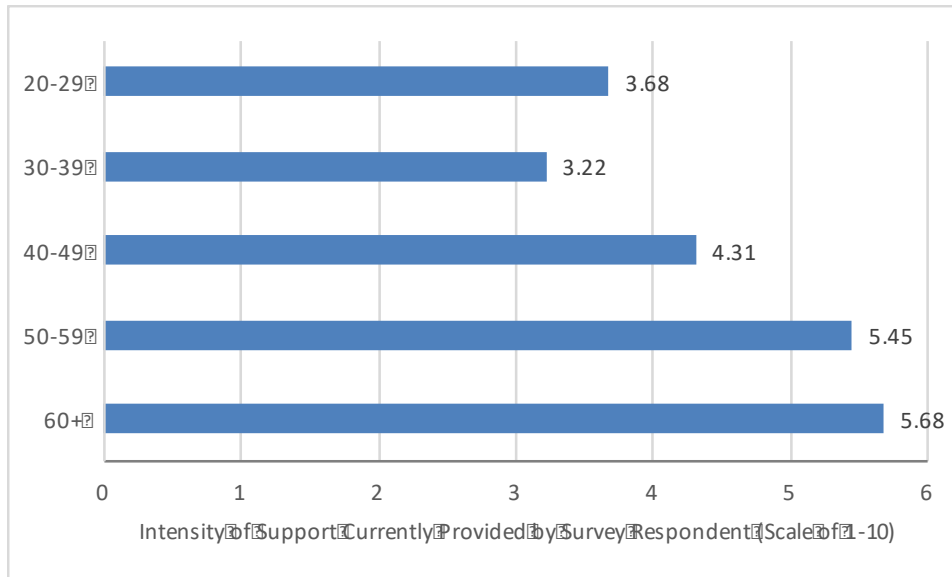
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<sup>4</sup> As the age category refers to the survey respondent, it should be noted that the brother or sister with a DD might fall into a different age category.

<sup>5</sup> Note that some respondents indicated their brother or sister with a DD was living in more than one location (e.g., with parents and in a group home).

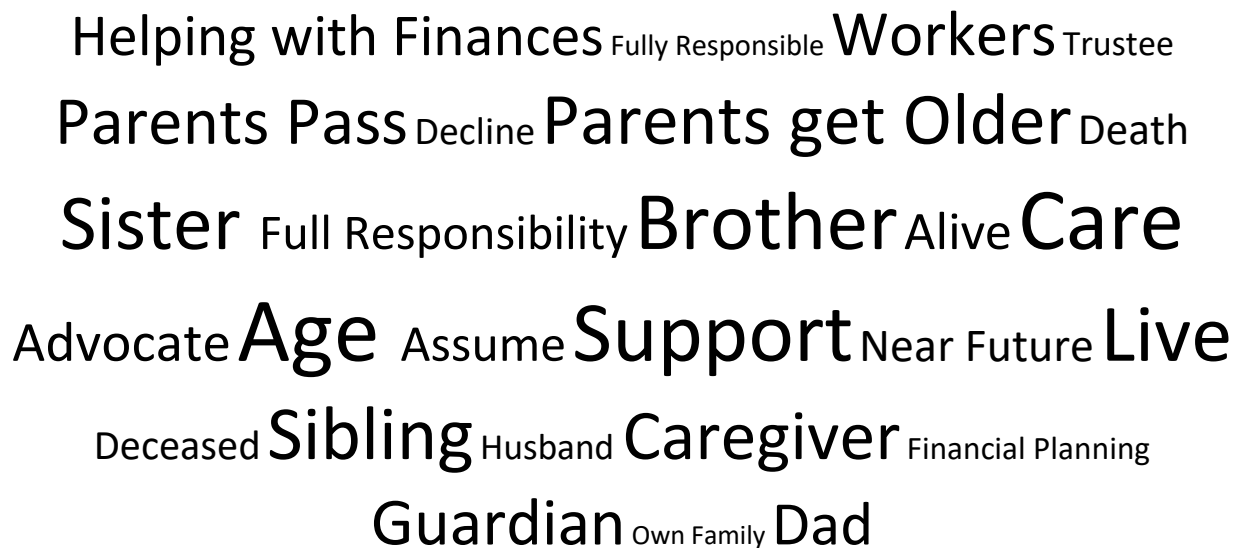
<sup>6</sup> Other includes: another family member, in a home share, with a friend, with a romantic partner, other specified.

**Figure 5. Intensity of Support Provided by Age Categories of Sibling Survey Respondents**



When asked whether they expect their role for their brother or sister with a DD to grow in the future, the majority of respondents to the question believed their role was either “very likely” (52.3%, n=173) or “likely” (19.9%, n=66) to increase. The reasons for an anticipated increase in support demands and responsibilities are illustrated in Figure 6.<sup>7</sup>

**Figure 6. Reasons for an Anticipated Increase in Supports Provided by Sibling Survey Respondents to their Brother or Sister with a DD Over Time**



<sup>7</sup> The larger the word appears in the graphic, the more frequently it was mentioned.

Some of the comments explaining the intensity of support include:

*“Parents still alive but 90 & 93. Mother still has control but can’t handle too much any longer. I will have most physical, medical, tax, ADVOCACY responsibility, but 2 siblings have Property POA of Trust fund.”*

*“Mom has died and my dad is becoming older and frailer.”*

*“My role increased this summer, when my brother had a stroke and I became his advocate in the hospital system for seven weeks of essentially daily contact.”*

*“He (brother) is aging prematurely and requires physical, mental and emotional support.”*

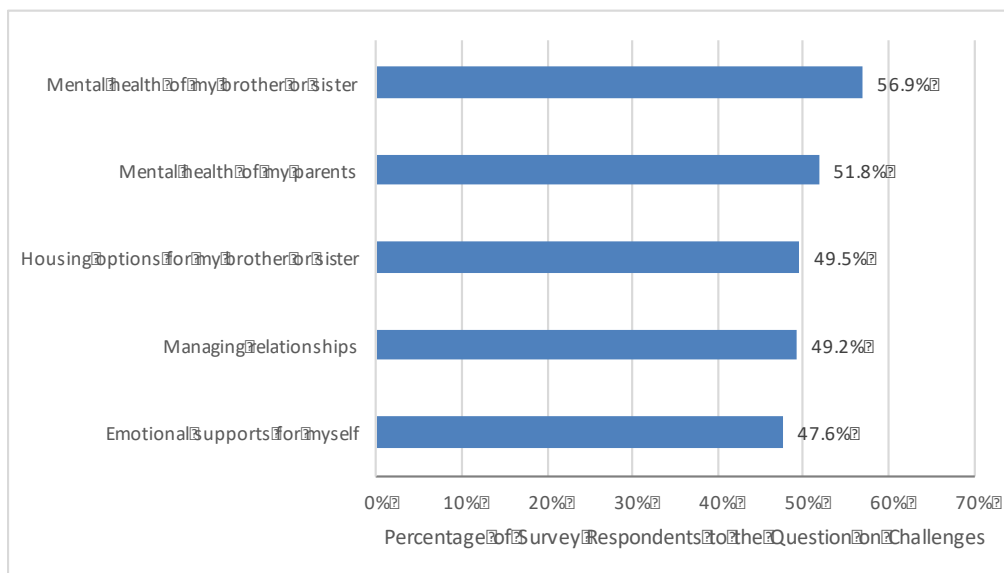
*“I expect my sister will come and live with me eventually. She can handle independent living with support, but is happiest in a home environment.”*

### **Current Challenges Identified by Siblings**

In response to the question “In what areas do you experience challenges in your role supporting your brother(s) and sister(s) with a disability?” siblings could select as many challenges as relevant from a list of 13. More than half of the 311 siblings who responded to this question indicated the mental health of their brother or sister with a DD (56.9%, n=177) and the mental health of their parents (51.8%, n=161) as challenges. Close to half identified housing options (49.5%, n=154), managing relationships (49.2%, n=153) and emotional supports for themselves (47.6%, n=148) as challenges.

While there was some difference in prioritization of the challenges depending on the age group, the main priorities are summarized in the following graph.

**Figure 7. Top Challenges Facing Sibling Survey Respondents**



Notably, the mental health of the brother or sister with a DD was consistently identified as one of three top challenges across all age groups.

Some of the comments explaining the challenges include:

*“Navigating the relationship with my parents and their role versus mine (and my sibling's) I find it hard to step in too much on finances, legal, housing, etc. at this stage.”*

*“Bereavement of multiple immediate family members.”*

*“I worry about my brothers having a fulfilling life.”*

*“My relationship with my husband.”*

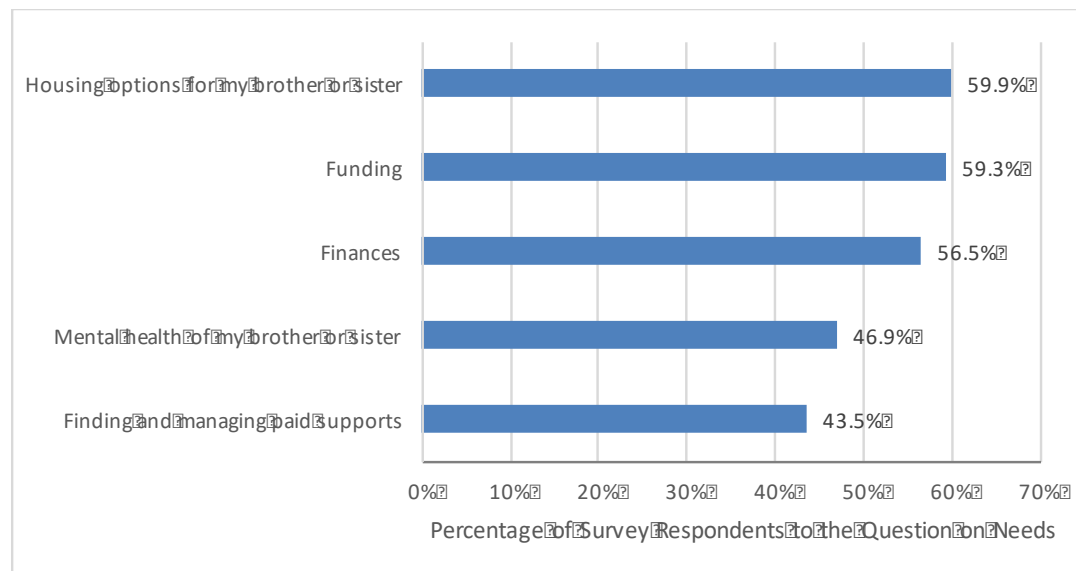
*“Seeing my mom do all the work for so long.”*

### **Current Needs Identified by Siblings**

Siblings were asked to pick the top five areas – from a list of 12 – where they would like tools, resources and information to help support their brother or sister with a DD.

Although there were differences in the ranking of the priorities, the responses were consistent across age groups. Overall, 60% of siblings who responded to the survey question on current needs were seeking tools, resources and information around housing options. The financial pressures (finances and funding) of supporting a brother or sister with a DD were also significant concerns throughout the lifecycle.

**Figure 8. Top Needs Identified by Siblings**



It was only among the younger adults (20-29-year-old) – at 54.5% (n=79) – that employment was listed as one of the top five areas for desiring tools, resources and information.

Finding and managing paid supports was not identified as a priority area for the respondents aged 60+, with 38.6% (n=10) indicating it was area where they would like tools, resources and information. Half (n=13) of this group, however, identified creative problem solving as a priority.

Some comments explaining the current needs of siblings include:

*“Long wait lists for new housing. 5-10 years. Little sibling assistance. Parents too elderly to assist.”*

*“Managing the red tape involved in any government program. Always dozens of phone calls, paperwork, authorizations. So many people involved in any program, this causes miscommunication. Too many hoops to jump through.”*

*“My brother spends every weekend with either me or my sister. He is 55 and when he was younger he would go to my parents' home every weekend from the group home where he lives. As our mother is 94 and lives in a retirement home that has not been possible for some years so my sister and I take turns having him at our homes. The difficulties are primarily logistical: as I live alone, and as he can't be left alone in my house except for very short periods of time, I'm very tied down every other weekend. This presents some difficulties (groceries, caring for my mother, etc.) particularly as I still work full time.”*

*“Problem solving 'care' practicalities and dealing with exhaustion.”*

## **Accessing Sibling Resources**

### ***Friends and family***

At 74% – and almost three times the next most selected option of another sibling supporting a brother or sister with a DD – friends and family were identified as the top source of information for survey respondents. However, focus groups and interviews show that family, specifically parents, often do not include or share information with their children and that adult siblings do not connect with each other (Rubin, et al., 2016). Despite being the top resource currently used by individuals supporting siblings with a DD, family and friends are not necessarily a reliable and comprehensive source.

### ***Online website***

When asked how individuals would prefer to access tools, resources and information to help them (by selecting three out of a list of 14 options), 65.1% (n=209) of individuals who responded to the question expressed interest in having access to an online website.

***In-person conference***

The second most popular response – from 35.2% (n=113) of individuals who responded to the question – was attending an in-person conference.

When asked directly “If an in-person conference was held in the Toronto area, would you be interested in attending?” 259 of the 325 who responded to the question expressed interest, with 40.6% (n=132) selecting “Yes” and 39.1% (n=127) selecting “Maybe”.

The key considerations for attending a conference that were listed by respondents are illustrated in the following figure.

**Figure 9. Key Considerations for Attending an In-Person Sibling Conference**



## Recommendations

1. While the sibling survey represents a good start at uncovering the needs and challenges of individuals with a brother or sister with a DD, siblings as a cohort require further study and analysis. In many cases, the lifelong wellbeing of individuals with a disability depends heavily on their sibling's wellbeing. As a result, we recommend carefully developing and launching a nationwide survey to gain a more comprehensive national perspective on the needs and challenges of siblings. This would represent a critical addition to the discussions on wellbeing and security for individuals with a DD in Canada and build on our initial findings outlined in this report.
2. We recommend that adult siblings connect with other siblings to share common experiences or concerns and to provide encouragement, comfort and advice. As discussed in our findings, adult siblings do not tend to connect with each other as a cohort. We suggest that organizations and individuals collaborate with the Sibling Collaborative to support a sibling symposium in 2019. A sibling symposium would be a chance for siblings from across Canada to connect as well as access and develop tools and resources that can assist them in better supporting their brothers and sisters with a DD.
3. We recommend that funding be allocated to the development of resources and tools that address the priority needs identified by siblings (e.g., housing options, funding, financing, mental health) as well as an online platform to house the resources.
4. Individuals with an intellectual disability face rates of mental illness that are three to four times higher than the general population (Canadian Association for Community Living, 2018). People who have mental health challenges and developmental disabilities are some of the most vulnerable persons in our society and healthcare systems (Lunsky, 2013).

As the sibling relationship is the longest familial relationship and siblings are likely to be the most constant companions in the lifelong journey of their brother or sister with a DD, they are apt to encounter the mental health challenges that arise. The individuals responding to our survey recognize this issue and are concerned about the mental health of their brothers and sisters with a DD. As a result, we recommend:

- a. The developmental services sector coordinate with the health (and specifically mental health) sector to provide access to mental health support services to individuals with a DD.
- b. The developmental services sector build capacity around mental health and individuals with a DD.

- c. Making investments, over a lifespan, in building a strong emotional base for siblings with a brother or sister with a DD to ensure their resilience, compassion and wellness. This can be done through the development of relevant tools, information and resources that are made widely available and accessible (see Recommendation 3).
  - d. Supporting the mental health of individuals with a DD as well as their siblings and families at an early stage to reduce their risk of crises over their lifespan.
4. Housing is a significant concern for siblings who anticipate having a role or responsibility for their brother or sister with a DD in this area at some point in their lifecycle. We recommend removing barriers, improving opportunities and supporting innovative and inclusive housing options for adults with a DD. We also recommend including siblings in these discussions and, in particular, the generation of creative solutions.
5. Funding and finances are also significant concerns for siblings who anticipate having a role or responsibility for their brother or sister with a DD in this area at some point in their lifecycle. We recommend a comprehensive national funding approach to ensuring Canadians with a disability have financial safeguards so they are not at risk of poverty, such as a Guaranteed Annual Basic Income for Canadians with disabilities. Quebec's minimum income program, Ontario's Basic Income pilots, advocacy for a refundable Disability Tax Credit and improvements to the Registered Disability Savings Plan (RDSP) all point to the need for a comprehensive approach to dealing with the reality that over 75% of adults with intellectual disabilities not living with family members are poor (Canadian Association for Community Living, 2013).
6. The survey identifies friends and family as the top source of information for siblings with a brother or sister with a DD. Focus groups, interviews and expert opinions, however, show that family (specifically parents) filter, exclude or do not share necessary information with the typical sibling. This could mean that the quality of information transfer from parents to siblings may not be adequate. Regardless, there is an opportunity while parents are younger and still in good health to include the typical sibling in the development of plans and the building of key relationships and support networks for the brother or sister with a DD.

We recommend that families including typical siblings in decision making and future planning at an early age and on an ongoing basis. This way an important exchange of information between parents (or families) and siblings can develop over a number of years. Parents or families should consider the support of a facilitator when feasible.

7. We recommend that organizations supporting families of an individual with a DD modify the language of their documentation, invitations and services to invite siblings into the conversation.



## **Limitations**

It is important to recognize that the findings in this report are largely drawn from a group of young adults as well as individuals residing in Ontario. Thus, it is not representative of views from across Canada. Finally, the results may be biased toward individuals with a certain degree of engagement with their siblings already.

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## About the Authors

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## Opportunities to Get Involved

This report is just the beginning. We hope that you will be part of the journey forward for those of us with a brother or sister with a DD.

If you would like to connect with other siblings online, [join our Sibling Collaborative Facebook group](#). If you have not already provided us with your email address and are interested in future events, meet-ups or information, [join our email list](#). Lastly, if you have any questions or concerns about this report, please do not hesitate to reach out to us at [info@siblingcollaborative.org](mailto:info@siblingcollaborative.org).