

A Guide to Running Virtual Peer Meetups for Adults Who Have Siblings with Disabilities



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About this Guide

This guide was created by Siblings Canada, an initiative of the Canadian Centre for Caregiving Excellence, to support organizations, agencies, and community groups in developing and delivering virtual peer meetup programs for adult siblings of people with disabilities.

In addition to highlighting the importance of supporting siblings of people with disabilities, it outlines who and what peer meetup programs involve, and offers practical recommendations for running a successful program at your organization, agency, or community group.

Acknowledgments

We would like to thank the Azrieli Foundation for their recognition of the valuable role siblings play in the well-being of their brothers and sisters with disabilities and for their financial support to develop this guide.

Siblings Canada

<u>Siblings Canada</u> strengthens and empowers siblings of people with disabilities to meet their changing roles with greater confidence and influence.

An initiative of the Canadian Centre for Caregiving Excellence, we raise awareness of the critical role siblings play in creating robust and responsive systems of care for people with disabilities. We also serve as a source of relevant knowledge, learning, and resources for sibling caregivers and the organizations supporting them.

Visit <u>canadiancaregiving.org/siblingscanada</u> to learn more about us.



Introduction

Who is this guide for?

If you represent an organization that serves people with disabilities¹ and their families² you're in the right place. While we refer to "organizations" throughout this guide, we have created this resource for **any organization**, **agency**, **or community group that wants to better support adult siblings**³ **of people with disabilities and their families**.

The importance of supporting siblings

Most organizations working with people with disabilities recognize the importance of supporting parents as they move through life with their children who have disabilities. In fact, there is a substantial amount of research, resources, and other supports available to help parents navigate the different stages of their children's lives, particularly the early developmental and school years.

Unfortunately, much less support exists for adults with disabilities and, by extension, their aging parents and other family members. Yet today, people with disabilities are outliving their parents more than ever before. As a result, siblings are becoming—or, in some cases, have already become—the next generation of primary caregivers for their family members with disabilities.

The reality is that many siblings are unprepared for this life-changing transition and lack the necessary support and resources for their new or existing roles and responsibilities.

A virtual peer meetup program—the focus of this guide—is one way your organization can intentionally connect with and support siblings as current or future caregivers.

¹ The term **disability** refers to a range of disabilities, including intellectual or developmental disabilities, acquired brain injuries, autistic spectrum disorder, cerebral palsy, mental health disabilities, and substance dependence and abuse, among others.

² The term **family** refers to the <u>Vanier Institute's definition of family</u>.

³ The term **siblings** of people with disabilities refers to siblings, siblings-in-law, cousins, and other second-generation caregivers.



How will this guide help your organization?

This guide will help build your organization's capacity to deliver impactful virtual peer meetup programs for adult siblings of people with disabilities.

While there are many benefits of peer meetups for adult siblings (which we'll cover later in this guide), we want to draw attention to the value that offering a program like this can bring to your organization.

Over time, the people with disabilities supported by your organization—and their family members—will experience life-changing transitions. In many cases it will be siblings who assume greater responsibilities for care of their brothers and sisters with disabilities, especially as their parents age or pass away.

A peer meetup program is a valuable way to engage siblings in your important work and begin to build rapport with them. Forming trusting relationships will serve as a solid foundation for long-term collaboration and decision making with siblings and ultimately lead to better outcomes for people with disabilities.



The Power of Connection

In 2021, Siblings Canada carried out a national survey of adults who have siblings with disabilities. More than 360 siblings responded. **Eighty-four percent of siblings said it was important they connect with other siblings**.

Recognizing this, Siblings Canada developed a successful virtual peer meetup program for adult siblings. More than 80% of participants rated their experience as either very satisfying or satisfying. Many participants expressed how much they valued connecting with other siblings they could share openly with and truly relate to.

This positive feedback comes as no surprise. Research demonstrates that peer meetups, like other peer support interventions, create <u>positive outcomes for</u> <u>participants</u>, including reduced isolation and an improved sense of connection and overall well-being.





Peer Meetups 101

Before you can design and deliver an effective virtual meetup program for siblings, it's helpful to go over the basics, including who and what is involved in an online meetup.

What is a virtual peer meetup?

A peer meetup is a form of peer support. Peer support is unique in that it is centred around reciprocity and a deep sense of understanding that comes from similar lived experiences. This is often the case for siblings of people with disabilities who may share common experiences, challenges, and characteristics.

Virtual sibling meetups are scheduled online gatherings of adults whose lives are affected by having a sibling with a disability. They are intended to create a welcoming and safe space for siblings to connect and share their experiences through guided group discussions.

Led by a skilled facilitator, most meetups are broken into the following segments:

- Introductions: (~10 minutes): Meetups open with introductions of the facilitator and participants and an overview of the ground rules (<u>see Page 9</u>).
- Planned questions: (~35 minutes): Participants walk through a few questions and related conversation points. The most effective questions are ones that are open-ended and draw out common experiences and emotions experienced by siblings (e.g., uncertainty around the future).
- **Committed action:** (~10 minutes): The final question is typically one that helps participants shift from reflection to action and encourages them to exchange ideas and resources with one another.
- Conclusion: (~5 minutes): The end of the meetup is an ideal time for facilitators to make relevant announcements (e.g., information on upcoming meetups, details on any follow-up surveys) and, time permitting, quickly check in with participants as to how they are feeling.



The role of the facilitator

Having a trained and skilled facilitator to plan and lead your meetups is critical to their success. Meetup facilitators might be employees of your organization, part-time contractors, or even volunteers. Siblings of people with disabilities are ideal facilitators as they can more easily relate to meetup participants.

The facilitator has several important responsibilities:

1) Planning the meetup:

- Developing a meetup theme and related discussion questions.
- Creating an agenda for the meetup.
- Promoting the event and recruiting the participants. (Note this might also be done by someone else within your organization.)
- Reporting any feedback or other issues that come up.

2) Leading the meetup:

- Creating a welcoming, respectful, and safe environment for participants.
- Establishing and clearly communicating the ground rules early on (see the next section for more on what these involve).
- Keeping the discussion moving in the intended direction.
- Ensuring everyone has a chance to participate.
- Managing difficult comments, conversations, or situations.
- Recognizing when someone may need additional support and, when appropriate, connecting outside the group.
- Sharing relevant resources.

Although they are the one asking the questions, guiding the discussions, and dealing with challenges that come up, **the facilitator is meant to listen more than talk**.

The need for ground rules



Successful peer meetups are guided by a set of ground rules that are intended to keep the discussions as productive as possible. While the individual facilitator or group might come up with additional ground rules, we recommend incorporating and clearly communicating the following principles at all your meetups:

- **Giving advice:** Offering unsolicited advice can come across as criticism. Because this type of advice can cause more harm than good, make participants aware that it is not welcome.
- **Being open:** Creating a safe space for participants to explore and share without fear of being judged or penalized helps ensure a supportive environment. Siblings are encouraged to come with an open mind and to suspend judgment of others.
- **Avoiding a burden narrative:** Although having a sibling with a disability can be challenging, participants should make every effort to speak of their family members in ways that are respectful and compassionate.
- **Emotional wellbeing:** Meetups are not therapy sessions. Participants are responsible for their own emotional wellbeing. If a sibling finds themselves becoming upset or distressed, they may need to leave the group for a break.
- **Side conversations:** During the larger group conversation, side conversations (e.g., instant messaging) should be discouraged as they can disrupt the flow and cohesion of the group discussion.

As the meetup unfolds, the facilitator can use their best judgement to ensure the participants are following the established ground rules.

Quick tip: When emailing participants instructions for the virtual meetup, include a copy of the ground rules so they can review them before the event.

The benefits of virtual peer meetups



A sibling's journey—regardless of the type of caregiving role they play in their sibling's life—can be lonely. Virtual peer meetups offer opportunities for siblings to connect with one another and reduce feelings of isolation and overwhelm. Over time, participants start to tap into and build new networks of support.

"I was tentative heading into this meetup because I've never really discussed being a sibling with other siblings before. This was cathartic beyond belief—my expectations were blown out of the water."

- Former meetup participant

There are many positive outcomes that siblings involved in our virtual meetups have reported experiencing:

- A sense of connection with other siblings.
- A feeling of being understood and accepted.
- A more positive outlook on the present or future.
- A greater understanding of how to navigate the 'system'.
- Ideas for how to strengthen their physical and emotional wellbeing.

As an organization, you will want to get clear from the outset on the outcomes you are trying to achieve through your sibling meetups. This will help with both recruitment and evaluation activities as you develop and deliver your own virtual meetup program, the topic of our next section.



Delivering a Virtual Meetup Program for Siblings

Now that you're familiar with what peer meetups are all about, you can begin to consider how you might create and deliver a virtual sibling meetup program of your own.

Before you get started, it is important to make some key decisions around the scope, size, and timing of your program. This is because the way you structure your program will depend on these and other factors, such as your organization's capacity and the needs of your participants.

Resource considerations

To develop and deliver an effective virtual meetup program for siblings, you will require several resources:

- A **program budget** that will sufficiently cover the associated costs, including facilitator fees and any additional staff time (e.g., coordination, communication, training, and evaluation activities) or online platform requirements. The budget will of course vary depending on the size and scope of your program.
- A **program lead within your organization** to act as a point person for the program. While the lead probably won't need to devote too much time to the role, it helps to have someone internal oversee the program and support the facilitators (e.g., working through challenging situations that may come up).
- A **trained facilitator**. As we mentioned earlier, successful peer meetup programs require capable facilitators who have both the knowledge and tools required to be effective. Opportunities to debrief and receive additional coaching are also beneficial to keep them at the top of their game. For these and other reasons, your program facilitators will require thoughtful training and ongoing support to feel empowered, confident, and motivated in their roles.

Note that Siblings Canada offers facilitator training should your organization not have this expertise in-house. Contact us at **info@siblingscanada.ca** for more information.



- Someone to manage **program coordination and communications**. This could be the program lead, facilitator, or someone else within your organization with experience in project coordination, communications, or marketing.
- **Online platforms** for meetup registration, hosting, and evaluation:
 - **Registration**: To streamline the registration process for participants, use an online platform like Eventbrite.
 - **Hosting**: To deliver sibling meetups virtually, you will need an online video conferencing platform (e.g., Zoom, Microsoft Teams, Google Meet).



Logistical considerations

Keep the following logistical considerations in mind when developing and delivering your virtual meetup program.

Timing

When planning a virtual sibling meetup, you will of course want to find a day and time that works for most people's availability—no easy feat. In our experience, we have found the following helpful when scheduling meetups:

- Holding the meetup between 6pm and 8pm (or sometime in the evening) during the middle of the week.
- Sending around a poll (e.g., Doodle) to figure out a day and time that works best for those who are interested in participating. This is also a good opportunity to find out how frequently siblings would like to attend meetups.
- Keeping time zones in mind if you have siblings attending from across Canada.

Participants



Virtual sibling meetups are meant for siblings, siblings-in-law, cousins, and any other second-generation caregivers.

Understandably, many parents are concerned and curious about sibling relationships and caregiving and, as a result, might like to attend a meetup. To ensure participants feel comfortable to speak freely, we suggest keeping meetups exclusively to siblings and the groups listed above.

We also suggest keeping them relatively small so that everyone has a chance to share. In our experience, eight to 10 participants are ideal. That said, because it is common for some participants to cancel at the last minute, you may want to allow up to 12 siblings to register for the meetup.

Frequency

If resources and demand allow, we recommend starting out by hosting a peer meetup every month or two. Once your program is more established, you can check with participants as to how often they would like to meet and consider altering the frequency.

Tips for successful virtual meetups:

- Keep events to 60-75 minutes.
- Create and follow an agenda.
- Host smaller groups (8-10 people).
- Hold shorter discussions more frequently.
- Stick to a regular day and time (e.g., first Monday of the month).
- Vary the meetup themes and topics.
- Offer theme-related resources.





Next Steps

If you would like to know more about how to develop and deliver a virtual meetup program for siblings at your organization, contact Siblings Canada at <u>info@siblingscanada.ca</u>.

Depending on your needs, we have additional resources and advisory services you may find helpful.

What's more, Siblings Canada has created an on-demand online orientation for organizations on how to better support adult siblings of people with disabilities. If you are interested in learning more, email us at info@siblingscanada.ca.

Finally, if you haven't already, we encourage you to <u>check out the Siblings Canada</u> <u>website</u> and <u>subscribe to the Canadian Centre for Caregiving Excellent newsletter</u>.