



A Guide to Running Peer Mentoring Programs for Adults Who Have Siblings with Disabilities

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About this Guide

This guide was created by Siblings Canada with funding from the Azrieli Foundation. It is intended to support organizations, agencies, and community groups to develop and deliver peer mentoring 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 mentoring programs involve and offers practical recommendations for running one.

Acknowledgments

This guide borrows from a manual produced by the Ontario Caregiver Organization that was informed by research, best practices, and consultations with caregivers. With permission from the organization, Siblings Canada has adapted some of the manual's content for the purposes of this guide.

We would also like to thank the Azrieli Foundation for their financial support to develop this resource.

Siblings Canada

[Siblings Canada](#) 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 canadiancaregiving.org/siblingscanada 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 siblings³ 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 life, 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 peer mentoring program—the focus of this guide—is one way your organization can intentionally connect with and support siblings to help facilitate good lives for the people with disabilities you serve.

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

² The term **family** refers to the [Vanier Institute's definition of family](#).

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 peer mentoring programs for adult siblings of people with disabilities.

While there are many benefits of peer mentoring 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 your organization supports—and their family members—will experience life-changing transitions. As we mentioned earlier, in many cases it will be siblings who assume greater responsibilities for care, especially as their parents age or pass away.

Peer mentoring programs are a great 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 said it was important they connect with other siblings, and more than two-thirds expressed an interest in mentoring relationships**, demonstrating both a need and desire for peer mentoring relationships among siblings.

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

The results are not surprising given how well-documented the positive impacts of mentoring are on both mentors and mentees. Peer mentoring programs create many benefits for siblings ([see Page 9](#)) and are a valuable complement to other types of support your organization may already be offering to families.

Peer Mentoring 101

Before you design or deliver a peer mentoring program for siblings, it's helpful to go over the basics, including what and who is involved.

What is peer mentoring?

Peer mentoring is a form of peer support that aims to supportive relationships between individuals as they share knowledge, experiences, and perspectives. Peer support is unique in that it's 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, or characteristics.

The role of a peer mentor

A peer mentor may hold a variety of roles and skill sets. Sometimes they spend more time in one role than another—it all depends on their peer mentee’s needs and goals. That said, there are some common responsibilities mentors carry out:

- **Support:** Mentors listen attentively, offer encouragement, and help build a trusting relationship with their mentees.
- **Learn:** Mentors ask questions to help mentees gain clarity on their situation and how they want to move forward; they help mentees identify their own unique strengths and skills which empowers them to make decisions and act.
- **Share:** Mentors share their lived experiences and give real-life examples.
- **Inform:** Mentors offer reliable and helpful information about programs and services for people with disabilities or other issues (housing, employment).
- **Plan:** Mentors support mentees to set specific goals and make plans.

It’s important to note that a mentor is not meant to take on the role of friend or counsellor. Mentors and mentees need to be clear about this from the outset.

What are peer mentors looking for?

Siblings volunteer their time as peer mentors for a variety of reasons. Often, they have gone through challenges or major life transitions related to being a sibling and want to share these experiences and their resulting lessons with other siblings. Being a peer mentor also comes with its own set of benefits, including a sense of purpose, social connectedness, and new perspectives and ideas.

“I think that I have gained as well. It’s been useful to hear how another sibling thinks about their relationship and their resources. It’s also been useful to articulate things about my own situation and reflect on those ideas.”

– Former Mentor

The role of a peer mentee

Peer mentees are responsible for identifying the topics and issues that are most important to them and sharing these with their mentors. Their needs help shape and direct conversations and inform the goals they set for their time in the program. While the goals they set may be directly related to their sibling with a disability, they might also be more personal in nature, such as establishing healthy boundaries to maintain a sense of self or creating more time to improve their own personal health and well-being.

Throughout the program, peer mentees should also be prepared to be honest and open; welcome questions and feedback; and ask for help.

Overall, by playing an active role in the relationship, peer mentees are more likely to recognize the unique skills and strengths they possess to confront challenges—whether today or in the future—ultimately building their confidence and optimism.

What are peer mentees looking for?

There are many reasons siblings may be looking for support from a peer mentor. Some may want to discuss major life decisions like school and work. Others may have experienced a significant life change, such as a parent becoming ill, that requires them to become more involved in their sibling's care or to engage in more planning for the future. Finally, some get involved with less specific goals in mind. They simply want to connect with someone who “gets it”.

“By working with a mentor, I think I’ll be able to get a clearer perspective of what’s best for both me and my sibling. I’m interested in experiences where the sibling moves away for school or a demanding career and how they were able to plan for this with their sibling in mind.”

– Former Mentee

The benefits of peer mentoring

Peer mentoring creates two-way relationships for siblings that can inspire positive change, growth, and self-discovery. They offer opportunities for siblings to connect with one another and reduce feelings of isolation and overwhelm.

“The most significant take away from the mentorship was the fact that it's ok not to be "perfect" and have everything figured out. I felt less alone and less powerless.”

– Former mentee

Siblings involved as mentees in our peer mentoring programs have reported a greater awareness of several important topics related to care and well-being:

- Creating a home for their sibling.
- Building natural supports and support networks for their sibling.
- Supporting mental health challenges, including grief.
- Understanding behavioural and emotional challenges of their sibling.
- Finding and maintaining employment for their sibling.
- Finding emotional supports for themselves.

As the list above illustrates, the benefits of peer mentoring extend beyond the direct participants to their siblings with disabilities and, at times, other family members.

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

Delivering a Peer Mentoring Program for Siblings

Now that you are familiar with what peer mentoring is all about and its many benefits, you can begin to consider how you might create and deliver a peer mentoring program of your own. Before you get started, it is important to consider your organization's capacity and the needs of your participants to make some key decisions around the scope, size, and timing of your program.

Resource considerations

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

- A **program budget** that will sufficiently cover the program lead position, communication requirements, mentor training, and evaluation activities. The budget will vary depending on the size and scope of your program.
- The right person to act as the **program lead**. This person will be responsible for developing and managing the program and will carry out a variety of tasks: conducting outreach, managing registration, creating matches, delivering training, supporting participants, and evaluating the program's success, among others. The program lead will work irregular hours (e.g., more hours during the intake phase and fewer while the program is being delivered). They will also need to work outside of the regular 9am-5pm office hours as many siblings require training and support during evenings and weekends.
- Someone to manage program **communications**. This could be the designated program lead, or it could be someone else within your organization with experience in marketing and communications.

- A comprehensive **training program for peer mentors**. Siblings Canada runs a well-received and cost-effective peer mentor training program that we deliver online. We recommend including it as part of your program. If you are interested in learning more about how we can help with peer mentor training, email us at info@siblingscanada.ca.



- **Online video conferencing platforms** to deliver meet-and-greets or training sessions. Siblings Canada’s mentor training program is hosted on Zoom. Other options include Microsoft Teams or Google Meet.

Recommended timeline

We suggest a 12-month timeline for peer mentoring programs. This includes time to set up the program, deliver it, and evaluate its success. Below is a high-level overview of how you might structure your program over the year:

Months 1-3: Program set-up

1. **Assign a program lead** to develop, promote, and manage the peer mentoring program.
2. **Clarify the size, scope, and goals** of your program. As mentioned earlier, this will depend on many factors, including your available resources. We suggest starting out with about eight to 15 sibling pairs.
3. **Develop applications and promotional materials** (for both peer mentors and mentees) and put out a call for participants.
4. **Select and train your peer mentors**. Successful peer mentoring programs require capable mentors who have the necessary knowledge and tools to be effective in their roles. For this reason, having a strong training program in place for mentors is critical. It results in mentors who feel empowered, confident, and inspired to support other siblings. We recommend that peer mentors are trained and supported by the program lead; this will ensure they have someone to help them troubleshoot any challenging situations that arise.

5. **Create thoughtful matches** between peer mentors and mentees using information from the applications. Consider factors such as where the applicant lives, the age of their sibling, stage of family life, and type of disability.
6. **Develop an evaluation plan** to gauge the program's success throughout the year and regularly incorporate feedback into program revisions.

Months 4-11: Program delivery

7. **Orient new peer mentees.** This involves providing them with a welcome document that lays out what to expect, the program's structure, and who to contact with questions or concerns. You may also want to host a welcome meeting for the mentees to go over these same topics and allow for questions. This could be done online or in person.
8. **Connect the matches.** Introduce the matches to each other. Consider hosting a "meet and greet" with the matches prior to the formal launch of the program—either online or in person. This might include introductions, ice breakers, a review of roles and expectations, and a question period.
9. **Ensure match commitment.** We suggest participants commit to eight months with their match and aim to connect at least six times over this period. Matches will need to decide together how they prefer to connect (e.g., online, phone calls, in person, or a combination).
10. **Provide ongoing support** to matches by planning for regularly scheduled check-ins with them every three months.

Month 12: Program evaluation and wrap-up

11. **Wrap up the program.** At the end of the year, take time to officially bring the program to a close and check in with each match. Depending on your evaluation plan, this could be informally through a phone conversation, formally through a post-program survey, or both.

Next Steps



If you would like to know more about how to develop and deliver a peer mentoring program for siblings at your organization, contact Siblings Canada at info@siblingscanada.ca.

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 [check out the Siblings Canada website](#) and [subscribe to the Canadian Centre for Caregiving Excellent newsletter](#).