



**A GUIDE TO
COMMUNICATING WITH FAMILY
for Adults Who Have
Siblings with Disabilities**

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About this Guide

This guide has been compiled for AIDE Canada by The Sibling Collaborative.

While we've made every effort to ensure the information in this guide is accurate and up to date, it should be noted this resource is not a substitute for professional advice. It is intended to help you better communicate with your family about the future and provide practical tools for engaging in healthy, productive conversations.

We cannot be held responsible for any actions you take after reading this guide.

Acknowledgments

We would like to extend a special thank you to [SibsUK](#). With permission from SibsUK, The Sibling Collaborative has adapted their workbook titled "[Talking to your parents about common sibling issues](#)" for the Canadian context.

We would also like to thank AIDE Canada for their financial support in developing this resource.

The Sibling Collaborative

The Sibling Collaborative is a Canadian network providing social, emotional, and practical support to adult siblings of people with disabilities.

We recognize that while the experiences of siblings are diverse and profound, our stories and needs are often overlooked or even forgotten as families wrestle with the pressing issues that affect their siblings with disabilities. We provide a voice and support to siblings of people with disabilities by connecting them with each other; creating or providing access to helpful and relevant resources; and advocating on behalf of them and their loved ones with disabilities.

Visit sibcollab.ca to learn more about our work and how you can get involved.

Introduction

Who is this guide for?

This guide is for adults who have a sibling* with a disability** who want to learn how to start or navigate sensitive conversations about the future with their family members***. If you're involved in the care or well-being of your sibling with a disability—or anticipate you will be in the future—you're in the right place. This guide will provide you with information, tips, and resources for having productive discussions with your family about the future.

Navigating these conversations is challenging and this guide will help you develop knowledge and skills to do so effectively.

Throughout this guide, the term **siblings of people with disabilities refers to siblings as well as siblings-in-law, cousins, and other second-generation caregivers.*

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

****When we refer to the term **families**, we follow the Vanier Institute's definition: "Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following:*

- *Physical maintenance and care of group members*
- *Addition of new members through procreation or adoption*
- *Socialization of children*
- *Social control of members*
- *Production, consumption, distribution of goods and services*
- *Affective nurturance—love...*

*[The] definition is inclusive of diverse family structures including (but not limited to) single parents, same-sex couples, stepfamilies, married or common-law couples (with or without children), skip-generation families and more."*¹

¹ <https://vanierinstitute.ca/definition-of-family/>

How will this guide help me?

As a sibling, you probably spend a lot of time worrying about the future of your sibling with a disability, especially what will happen when your sibling's primary caregiver (often your parents) is no longer able to care for them, and how it may impact your life.

Talking about such significant life changes, which involve aging and death, can bring up a wide range of emotions. Some families can talk about the future quite easily, others can only talk about certain parts, and some families have difficulty talking about it at all. For siblings, not knowing the plan—or not being included or considered in the planning process—can be equally emotional.

This guide will help you start or continue conversations with your family about the future.

Thinking About the Future

Imagining the future is hard at any age. Who knows what tomorrow will bring, let alone what will happen in 5, 10, or 30+ years from now?

When you have a sibling with a disability, imagining the future can be even more challenging. It involves difficult emotions, complex systems, and a lot of unanswered—or even unanswerable—questions. Questions like where your sibling will live, how their needs will be financed and met, what their health will be like, how much care you'll need to provide, and how you'll provide that care when you have your own family, work, and life to think about... And then of course you also need to ask and respect what your sibling wants for their life.

It's very likely your other family members have also been thinking about these things, perhaps for longer than you have—and they may have ideas, plans, and resources in place that you don't know about. If they don't, that's also important to know.

More than a quarter of adult siblings haven't had any conversations about the future with their families.

- Sibling Collaborative 2021 survey

Building a common understanding among your family of what the future will look like in different scenarios and visiting it regularly together is important; it will help reduce stress and ensure everyone's quality of life stays intact when things do change.

Why have these conversations?

Building a common understanding in your family of what the future holds is important for everyone, at all ages and stages of life. Many people believe future planning is just about money, but there are a wide range of considerations that involve each family member's individual dreams, aspirations, and vision for their life.

When you have a family member with a disability, thinking about the future goes far beyond dreams, goals and even finances. It often includes difficult discussions on a range of detailed and complicated topics:

- Daily needs and support
- Living arrangements
- Medical care, including medications, the aging process, and mental health
- Finances, including assets, income, estates, trusts, and insurance policies
- Legal, including powers of attorney, decision making, and wills
- Decision making support
- Daily activities, such as work, recreation, religion, and seeing friends

Because each of these topics on their own can be vast, confusing, and overwhelming, you'll want to decide as a family where your priorities lie and then discuss the items in manageable pieces. (More on this in the sections below!)

Getting the Discussions Started

Below we discuss how you can effectively prepare for what might be difficult, and even scary, conversations with your family, as well as some of the logistical factors to consider like timing and location.

Including your siblings

It's important to include your sibling or siblings in this process, in particular your sibling with a disability. Making decisions about the future of your sibling with a disability without their participation would be exclusionary—and possibly harmful in the long run. This doesn't mean that everyone in your family needs to be part of every conversation about the future; there may be times when you just want to speak to your parent(s) or your sibling(s). But you'll want to get a sense of everyone's perspectives, desires, worries, and ideas as you move through the different discussions and incorporate these into your family's plans.

Getting prepared

It may feel odd to consider planning a conversation with your family, especially when you can't plan for how they'll respond. However, like most tasks, being prepared will help build your confidence, reduce your anxiety, and improve your chances of a positive outcome. Before you approach an important conversation with your family:

- **Have clear aims.** What do you want and why? What is important to you and what are you willing to compromise on? Write this down and re-read it privately before you begin. Stick to one topic at a time.
- **Practice your skills.** How will you get across what you want or need? Have a look at the conversation strategies in this guide as you prepare.
- **Acknowledge how you feel.** Are you feeling anxious, angry, upset, ignored, or hurt? Write about your feelings first. Getting clear on how you feel about a topic can help you to communicate it. It can also help reduce the intensity of strong feelings, which can sidetrack a conversation.
- **Have a support plan ready.** What might you need during the conversation? For example, if you find your family members put you on the spot or go off topic, have a key phrase ready that you can reach for when your mind goes blank.
- **Keep an open mind.** Approach the topic as an open discussion or problem to be solved. Thinking of the situation as having a right or wrong outcome can close your mind off to further possibilities.

And remember—if your plan doesn't unfold the way you intended, you can review and adjust it for the next time.

Location, location, location

It's important to think about where you'll have your conversations and how your family might respond in different environments. Just think of the contrast between the comfortable and softly lit atmosphere of a therapist's office and a cold and intimidating police interview room.

You may find that because of current circumstances your only option is to hold the conversation at your or your family member's home. Wherever it takes place, try to limit distractions, and keep the environment as quiet and comfortable as possible.

Another idea is to try a neutral location that's comfortable, such as a coffee shop or local park. You might prefer a location like this as it's a fresh environment without the physical reminders of the family home. Perhaps most importantly, neutral settings can help you and your family members feel you're on an even ground and therefore better consider one another's point of view.

Timing is everything

Regardless of whether you've started talking about the future with your family, the best time for these discussions is now.

It's unlikely you'll have just one conversation with your family about the future. In fact, ideally your plans will unfold over a series of discussions that take place over many years, as life and circumstances change.

45% of siblings say they have started conversations with their family but there is more to discuss.

- Sibling Collaborative 2021 survey

Depending on the topic you want to discuss, you might find one of the following approaches helpful:

- **Indirect: little and often.** Bring up the topic regularly and with a little bit of context. For example, "I recently set up a bank account for my daughter and it made me think about money that I'd also like to put aside for Sarah's future. Do you and dad have a trust fund for Sarah?" This informal approach can feel more natural and gives your family members time to digest the information. Keep it to one small question at a time, and whatever the answer, acknowledge that and move on.
- **Direct: set aside a day and time.** For difficult topics, it's best to plan in advance. Tell your family members that you'd like to talk about the topic (e.g., your sibling's housing options) and mutually agree on a day and time to connect on it. Don't be disheartened if they're dismissive of this at first—your request may just have taken them by surprise. Leave it for now and bring it up again soon. Be gently persistent with your need to arrange the conversation, as this lets your family know how important it is to you.

Talking about the future can be painful for our family members and they may try to avoid the subject. Even if your family can't or won't engage with you about the future right now, it doesn't mean you should bury your questions and worries. Write down all your concerns and wishes. How much involvement would you like in your sibling's life and in what ways would you like to have this? Talk to a trusted friend, do research online, or seek counselling. Ideally, the time will come when you can share your thoughts and feelings with your family.

Communication Tips to Keep in Mind

When our family includes a person with a disability, home life can already feel maxed out. Family members, particularly primary caregivers, are absorbed with our siblings—thinking about their schooling, employment, housing, finances, and more. On top of these challenges, they may be feeling many difficult emotions...and then you come along wanting to talk about the future!

So, what can you do to help ensure the conversation goes well?

Be prepared to listen

Some siblings have naturally honed their listening skills through regularly listening to others and rarely expressing their own opinions. Other siblings may find it difficult to listen when it feels as though they've seldom been listened to themselves, including by their family.

To listen means to really pay attention to what the other person is saying. Also, as a bonus, when you listen well to others, you're more likely to be listened to in return.

- **Let them speak.** When your family members are speaking, avoid interrupting or correcting, even if you really disagree with what's being said. Wait until they've finished before responding.
- **Focus entirely on them.** Focus on their face, body language, words, and tone of voice. There are often clues to understanding in those cues.
- **Aim to understand.** While your family member is speaking it's tempting to start constructing a response in your mind. When you do this, however, it distracts you from listening and you may miss key information. Keep your mind focused on simply understanding what they are saying.
- **Check understanding.** If something isn't clear once they've finished speaking, ask them to repeat parts or say, "I'm not sure what you mean, can you help me understand?". Try not to make assumptions about what's being said.
- **Summarize.** When your family member has finished speaking, try summarizing what they've said in your own words. This acknowledges that you've listened and understood. It also gives them the opportunity to correct you if you've misunderstood them.

Recognize that language matters

No matter how hard we try, it's easy to be misunderstood. Thoughtful use of language can help reduce misunderstandings in your discussions.

- **Use simple sentences.** Discussions about the future and uncertainty can be emotionally difficult. When you're upset, it can be harder to listen and take in information. Use short sentences to get key information across.
- **Own your feelings.** Your feelings are yours alone; they are your subjective experience. A statement such as, "You make me so angry" can be argued with and your family member may feel blamed. A statement such as, "I feel angry" is harder to argue with as it's simply about how you feel and isn't placing any blame.
- **Use "let's" and "this".** It can be difficult to receive advice from family. Instead of using "you", try "let's" or "this". For example, "You really need to figure this out" can be rephrased to "Let's figure this out together" or "This is important and needs to be figured out". These may seem less accusatory and keep the discussion open.
- **Be specific.** Avoid hints and be clear about what you need. Stick to specific actions and suggest what you'd like to change. This will help your family see something they could do differently, rather than feeling they're flawed as people.
- **Use "and" instead of "but".** The word "but" discounts what's been said before it. Consider the difference between "I know this is hard for you *but* it's hard for me too" and "I know this is hard for you *and* it's hard for me too". The second statement has the same information and acknowledges you both. It can feel strange to use "and" instead of "but" at first, so practice until it feels more comfortable.

Manage conflict

It's inevitable that conflicts will arise when you're having discussions on topics as sensitive as the future. Each of your family members has their own personal experiences, histories, relationships, and perspectives, leading to unique opinions on what might be best when thinking about living arrangements, finances, and quality of life (among other topics!).

Here are some ideas for working through disagreements:

- **Stay calm.** The more important the conversation, the more heated it can get. If you feel things are heating up, take time to breathe or pause.
- **Prioritize.** If you're disagreeing on several topics related to the future, address which are most important and discuss those first. You might want to consider setting some topics aside completely for another time.
- **Get support.** Don't underestimate how emotionally and mentally draining having intense conversations can be. Make sure you're supported before and after the conversations. Discuss with your partner, share with a trusted friend, or connect with a sibling support group.
- **Consider counselling.** If you feel your family discussions are beyond repair or not making any progress, consider family counselling. If your family doesn't want to participate, you can always go on your own. Though it may seem pointless, discussing the situation openly with someone neutral can be quite helpful. You may be able to re-enter the conversation with your family from a fresh standpoint and feel more empowered.

Reflective Practice

Once you've made it through a tough conversation with your family, take some time to think through how it went. As we've mentioned throughout this guide, there will likely be many conversations, not just one.

Ask yourself these questions:

- How did that go?
- What will I do next?
- How can I support myself during this?

Take time to monitor your strategies and your efforts in this area. Practice and re-adjust your plans as needed. Most importantly, be kind to yourself, be patient, and make sure you have the support you need.

Having conversations about a topic as important as the future will be difficult and emotionally charged, no matter what the circumstances. But the investment you make in these discussions with your family members will be incredibly worthwhile as circumstances change and life unfolds.