

Family support groups provide safe spaces to connect and share information and resources. This fact sheet gives some direction to parents, grandparents or other caregivers who want to start a support group.



Why Start a Family Support Group?

- Connect with other families who are going through similar experiences
- Empower families to problem-solve
- Encourage families to become better advocates for their children
- Provide opportunities to learn about programs and services
- Gain a better understanding of their child's condition
- Provide respite, or time off, from direct caregiving

“Being part of a support group has been so important for my mental health. I feel less isolated and I learned so much from other parents.”



Is There a Need?

Starting a family support group takes time, energy and dedication. Before starting a new group **make sure there is a need**. To find out if a support group already exists, contact agencies like your Wisconsin Regional Center for Children and Youth with Special Health Care Needs (CYSHCN), your local community center, clinic, hospital or statewide disability organizations.



Getting Started

Begin by bringing together a small group of parents, family members or caregivers to form a steering committee. This group will be responsible for deciding on the **purpose, format, logistics, ground rules** and ways to **promote** the group.

The decisions made by the steering committee will set the tone and direction of your group, so it's important that this committee thinks through each of the following areas carefully before inviting members to join.

1st: Create a Purpose Statement and Objectives

Take the time to talk about your group's purpose and why you see the need for a support group. These discussions will lead to your objectives.

- Is your purpose to share information and resources, and connect families?
- Do you want to support each other and increase your ability to advocate for your family?
- Are you running into barriers that make parenting a child with special needs more difficult?

Whatever your reason, it's good to **have it in writing**. You can use your statement to promote your group and share with new members.

Want to Learn More?



Check out these resources to learn more about Support Groups:

- nacac.org/help/parent-group/start-parent-group/
- support4nicuparents.org/wp-content/uploads/2016/08/Starting-a-Peer-Support-Group-Aug-2016.pdf
- wikihow.com/Start-a-Support-Group

2nd: Decide on the Format

Decide how you want to meet. A group can meet face-to-face, over video, on teleconference calls, or through online communities. A parent or caregiver who shares the group's purpose and has lived experience is often chosen to lead the group as a facilitator for the meeting. The facilitator may be paid or may volunteer. Some groups choose to be led by a provider like a teacher, therapist or social worker.

Think about how you want your group to run. Meetings can begin with the facilitator introducing a topic or asking a question, or it can be less formal and open to what members want to share. Guest speakers can also be invited, especially when there's interest in learning more about a topic or program that benefits all members.

3rd: Logistics

Decide **when**, **where** and **how often** the group will meet. It's a good idea to be flexible and revisit these decisions as new members join to make sure these decisions still work for everyone.

There are a lot of buildings that may be available for your support group to meet at **no cost**. Think about asking community centers, churches, libraries, coffee shops, schools or daycare centers for use of their facilities. Hospitals and clinics also often have conference rooms available. Meeting at support group members' homes is another good choice.



A Good Idea!

Ask local businesses or organizations if they will help sponsor your group. They might provide free snacks or coffee, *"When we asked if we could meet at a local café and told them about our group, the manager offered to provide free refreshments!"*

4th: Agree on General Ground Rules

It's important to have agreed upon ground rules to encourage members to feel comfortable in sharing personal experiences and emotions. Examples of meeting ground rules include, showing respect and courtesy to all members, and making sure personal information shared at group meetings stays within the group, unless express permission is given. The facilitator may need to speak up to enforce these rules if they are not being followed.

5th: Promoting the Group to Find Members

Your group's purpose statement can be used to develop your outreach materials. A few inexpensive ideas include, making a flyer to post at the library, grocery store, school, or clinic; asking schools or community agencies to promote your group; and, using social media, like Facebook.

Don't worry if membership is small at the beginning. Give it time to build as families learn about your group. You will learn along the way what works well and what can be improved. Your group **can make a difference**, so families and other caregivers feel supported, connected and empowered to better care for themselves and their children with disabilities or special health care need!



Still Have Questions? Need Help Finding Services for Your Child?

- [Regional Centers for Children and Youth with Special Health Care Needs](https://dhs.wisconsin.gov/cyshcn/index.htm)
dhs.wisconsin.gov/cyshcn/index.htm
- [Well Badger Health Resource Center](https://wellbadger.org) wellbadger.org or call 800.642.7837