

# Developing a Family-Centered Policy Agenda

## Best Practices and Lessons Learned

A strong, family-centered policy plan is built on partnerships—especially with the people who will be directly affected by the policies. Families play a key role in shaping policy and making sure it works in real life. Their voices, experiences, and ideas are the foundation for creating policies that truly support children and youth with special health care needs.

By using the best practices and lessons we learned while building our policy agenda, other organizations can start strong partnerships with families and groups that share similar goals. At Family Voices, we also work hard to follow our own advice—always learning from what works and what doesn't. This helps us keep improving how we work with others and how we create policies that make a real difference.

### Best Practices

- 1 Partner with your Community.** Your community consists of the people your organization serves, as well as the broader community that is affected by your organization's work and influence.
- 2 Engage External Partners.** Amplify the voices of your community by working with other organizations that share similar mission, values, and goals.
- 3 Be flexible and adaptable.** The larger policy context can change with political parties and their respective agendas.

These best practices here are explained in further detail on the following pages of this document, along with examples from our organization's process for developing a policy agenda.



# 1 Partner with Your Community.



**Listen to what your community has to say.** Hear what their priorities are through various methods that meet them where they are and happen when they can meet.



**Engage with youth leaders and advocates.** Treat their experiences and knowledge the same as you would for adults or professionals.



**Recognize staff as part of the community.** Members of your organization's staff may bring their own lived experiences, in addition to their experience in your organization. Those different perspectives can add context to the policy priorities for your organization.



**Be consistent.** Partnerships are built on relationships. Relationships are built through consistency and trust. Start the conversations and relationship building now. Don't wait until you need feedback, sign-ons, and quotes. Share back what you develop, and keep the conversation going.



## Family Voices Spotlight

Family Voices builds everything we do on strong partnerships with our community. Our community includes families and youth leaders who speak up for children and youth with special health care needs (CYSHCN) and disabilities. These leaders come from all 50 states, Washington, D.C., five U.S. territories, and three tribal nations. Their voices help guide our work and make sure we're focused on what really matters to the people we serve.

In the first few months of building our policy goals, we invited youth and family leaders to join policy listening sessions. During these sessions, we shared our early list of priorities—based on our organization's strategic plan—and asked for their thoughts. Their feedback helped us shape the direction of our policy agenda and make sure it reflected what really matters to the people we serve.

Many of the staff at Family Voices have personal experience with the challenges of getting care and support for children and youth with special health care needs (CYSHCN). When we created our first list of policy priorities, our staff gave feedback based on what they've seen in our programs and what they've gone through themselves. Their real-life experiences helped us better understand how state and local policies affect families and made our policy agenda stronger and more realistic.

Because we've built strong relationships and trust with our community, we were able to set up feedback sessions on our policy goals quickly. We keep building that trust by creating easy-to-understand materials about policy and by making space for open conversations. These conversations help us improve our materials and make sure they really work for the families and youth we serve.

## Engage External Partners.



Share your policy goals with other groups—especially those working on similar issues or whose work might be affected by your goals. This helps build stronger partnerships, avoid confusion, and make a bigger impact by working together.



Join and work with groups (called coalitions) that care about the same policy goals as you. These groups can help you think through how your ideas might affect different people and make your plans stronger by bringing in different points of view.

### Family Voices Spotlight

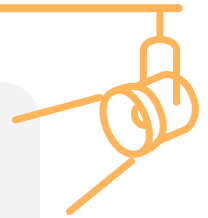
Family Voices works with many groups and coalitions that care about the same issues we do and support the families we focus on.

When our priorities come up in state or national policy discussions, we take the chance to look at how different decisions might affect people. For example, being part of bigger groups helped us understand what could happen if changes were made to Medicaid during the 2025 budget planning.

After we study the possible effects, we share what we learn with our network, along with clear steps people can take and messages they can use to speak up.

We also work closely with our partner groups to find chances for family and youth leaders to share their personal stories. These stories can be shared in writing or by speaking at events.

For example, through our partnership with Georgetown Center for Children and Families, we amplified the stories of families of CYSHCN and their experiences with Medicaid. In another case, through one of our coalitions, we supported a family leader in sharing their experience with Medicaid and the overall landscape of the children's health system with the bi-partisan Children's Health Caucus. These real-life stories help decision-makers understand why these issues matter.



### **Be Flexible and Adaptable.**



If your organization does not have the time or tools to keep up with policy news and current events, that's okay—you don't have to do it alone. Team up with other organizations or networks to help gather important updates and figure out how new policies might affect the people you care about. Working together makes it easier to stay informed and take action.



What matters most to your community can change depending on what's happening in the world. That's why it's important to have ways to regularly check in with your community and make sure your policy goals still match their needs. Create simple ways to listen—like surveys, listening sessions, or social media polls—and review your priorities often to stay on track.

## **Family Voices Spotlight**

While Family Voices was creating our 2025 policy goals between October and December 2024, the U.S. elections were happening. This made things uncertain because we didn't know which political party would be leading the country or what their priorities would be.

We worked carefully to build a policy agenda that stayed true to our mission of supporting children and youth with special health care needs (CYSHCN) and their families. At the same time, we made sure our goals were flexible so we could adjust how we reach them depending on the new leadership. Since the election, we've been paying close attention to how our priorities fit with the current administration, what messages will help us move forward, and how we can lift the voices of our community.

At the same time, we stay connected with families through regular conversations. Every few months, Family Voices holds policy listening sessions that focus on one part of our policy goals. We choose topics based on what's most important in national policy at the time. These sessions give us a chance to share updates on what we're working on—like advocacy and partnerships—but the main goal is to listen. We want to hear what's working, how policies are affecting families, and what changes are needed. This feedback helps us keep our policy goals up to date and focused on what families really need.

We also collect feedback through a yearly survey and a special project called the **Family Stories Storybook**, where families can share their experiences. You can learn more or submit your story by checking out the [Family-Centered Storytelling Guide](#).



## Lessons Learned

While Family Voices experienced success in developing our policy agenda, we also learned ways to improve our process.

**It's important to involve families right from the beginning.** Our programs are led by and shaped by families, which allowed us to include youth and family perspectives from the start. Their experiences are key to making sure our policy agenda truly reflects what communities need. Our first set of priorities was based on a combination of family perspectives and input from experts inside and outside our organization. We spoke with youth and families several times before finalizing our policy goals.

**It's also important to include partners who aren't usually part of policy conversations—**people or groups who are often left out of decision-making. This can include families from U.S. territories, tribal nations, or even fathers, all of whom are sometimes overlooked in conversations about children and youth with special health care needs (CYSHCN). While policies affect these groups, they often don't get the same attention or support as others. Including their voices helps make sure policies are fair and work for everyone.

## Policy Development Resources

- Learn more about our work to develop family-centered policy priorities and tools at [familyvoices.org/publicpolicy](https://familyvoices.org/publicpolicy).
- **Sign up** for our monthly policy e-newsletter, *Washington, DC Update*, for plain language summaries of current policy issues.

