

# Becoming a Family Advisor

As a parent you have much to offer, teach, and share. You bring unique experiences, perspectives, and expertise. Everyone benefits when families and providers work together to improve mental and physical healthcare, education, and community life for children with special mental and physical health and/or developmental needs. We hope to give you general information and guidance on what's involved in becoming an effective family advisor, no matter what setting you choose.

A family advisor is a parent or other family member who draws on personal experiences to influence decisions and help shape programs and policies. This may include a wide variety of activities such as: being a member of an advisory council, board, focus group, community coalition or becoming a reviewer of written or web based materials, or being a program evaluator, teacher, trainer, speaker and/or mentor to other families.

## **By getting involved as a family advisor, you will:**

- Reflect and share personal experiences, observations and family perspectives.
- Pose thoughtful questions and give feedback.
- Suggest ideas and propose solutions.
- Educate others.

## **In the rest of this guide you will find general guidance for becoming a family advisor:**

- Find opportunities to become a family advisor
- Decide if an opportunity is the right fit for you
- Consider how much to share about your child and family

## **And tips to prepare you for a specific family advisor event:**

- Educate others by telling your story
- Give feedback and share your ideas at meetings
- Training [put in training info](#)

## **Find Family Advisor Opportunities**

Interested in becoming a family advisor? It makes sense to start looking for opportunities by contacting people and organizations that you know to learn about what opportunities might exist:

- Ask other parents about ways to get involved

- Let your child’s mental or physical health care providers, teachers, therapists and community service providers know you are interested in getting involved
- Contact community based organizations (ie. Parent-to-Parent, Father’s Network, Medical Home Leadership Network)
- Talk with diagnosis specific organizations like the Epilepsy Foundation or Autism Speaks
- Contact OFSN

## **Is It the Right Fit For You?**

Becoming a successful family advisor is a role that most people grow into—it is the result of many factors, including:

- Self-awareness
- Listening and communication skills
- Commitment to collaboration
- Practice

When looking for or accepting family advisor roles, it is important to ask questions and get the right information so you are clear on what you will be asked to do. Then you can decide if it is a good fit for you at this time.

### **Understand what is being expected:**

Questions to consider include:

- What is the purpose and format of the meeting or event?
- When and where will it be and how long is the commitment?
- Who will be there and what is important to know about them?
- What would be your role?
- How should you prepare?
- Who would be your contact?

### **Ask yourself:**

- Is this important to me and is it something I want to do?
- Will this work for me?
- Do I have something to offer on the topic?
- Do I have enough perspective on our family's situation to effectively discuss the topic?
- How comfortable am I talking about my child and family?

## **Consider How Much to Share**

How much should you share about your child and family if you become a family advisor? Talking about your personal experiences can be a very effective way to illustrate a point and influence people's thinking.

### **Self-disclosure makes good sense when:**

- You're at a time and place in your life where you have some perspective on your situation.
- The story has benefit for others. It's not about your personal agenda, frustration, or current issue.
- You feel ready to share it. Trust your instincts. Share those parts of the experience that you feel ready to talk about. It is fine to keep some parts private.
- You are relatively comfortable talking about your experience. You don't feel overly vulnerable, exposed or shamed by sharing the story with others.

### **Guidelines for self-disclosure:**

- Stay with the focus of the conversation and the point you want to make—less is usually better.
- Protect the privacy of others. Be mindful about what details you share about whom. Stick with *YOUR* experiences.
- Make sure you get permission from your child or spouse before you share stories about them.

## **Teaching Through Your Stories**

Stories are an effective way to teach and influence people's thinking. Stories are personal and their images stick with listeners in ways that abstract ideas and data don't. Whether you are invited to tell your story as an informal talk to a few people or to give a formal presentation to a large group, the more prepared you are, the better chance you have at delivering a clear message that makes an impact.

Here are a few tips to help you **effectively tell your story** as a family advisor:

- **Construct a story that will teach:** Take time to reflect on your experiences. Decide on the particular point you want to make. Write down a portion of your personal story that teaches that point. Try using the 4 step framework included in the handout to help you with this process.
- **Get the feedback you need:** Seek feedback from those you trust. Get it early on. Ask for what details you could leave out and what would make your presentation stronger.
- **Deliver a polished presentation:** Recognize this involves managing nervousness, practicing good communication skills and being prepared in case you get emotional.

- **Respond to questions and answers:** Anticipate what questions the audience might ask and think through how you would answer them. Listen well, be brief in your responses and positive whenever possible.

## **Participating in a Meeting**

Whether you are asked to join a committee that meets on a regular basis or provide feedback in a one-time focus group, or something in between, participating in meetings as a family advisor is important work. A small but important shift occurs when you become a family advisor. You move beyond advocating for your own child and family to collaborating with others for the benefit of all children and families. To be effective in this role, you must have a strong sense of self combined with good listening, critical thinking and communication skills.

Here are some tips to help you **effectively participate in a meetings** as a family advisor:

- **Begin slowly and thoughtfully:** Observe others and listen well. Ask thoughtful questions. Be mindful of how you communicate as this will go a long way to insuring your input is well received and on target.
- **Recognize there are different ways to give constructive input:** Support and affirm what is going well. Offer feedback based on your direct experience. Provide suggestions/ideas/potential solutions for the future and/or respectfully express your differing viewpoints.
- **Tell your story in 30 seconds or less:** Share a short personal story in order to help make your point, but be careful not to lose your listeners by including too much detail.
- **Be aware you may have an emotional response:** discussions can bring back powerful memories that trigger emotions. Learn and practice what strategies for staying calm and grounded will work for you.

## **Effective Meeting Participation for Family Advisors [Put in training info](#)**

### **Helpful Ways to Begin: Observing, Listening and then Communicating**

As a family advisor, you will bring valuable information and ideas to a discussion. Listening well, asking thoughtful questions and being mindful of how you communicate will go a long way to insuring that your input is well received and on target.

Some tips for effective meeting participation include:

#### **Prior to the start of the meeting, get the lay of the land**

- Pay attention to the culture and style of the meeting
- Be certain you understand the focus of the meeting
- Make sure you are clear what you are being asked to comment on

#### **Ask good questions**

- Ask clarifying questions (example: “Let me make sure I understand correctly, are you saying...?”)
- Ask for jargon to be defined (example: “I’m not sure I know what CSHCN means. Would you please explain it to me?”)
- Ask for more details (example: “Can you walk me through this so I can imagine it?”)

**Think before you speak**

Psychology Ph.D. John Gottman says, “How you enter a conversation can be fateful”. He describes “soft start-ups” as an effective way to increase your chances of really being heard by others. Examples of “soft start-up” used successfully by family advisors include:

<ul style="list-style-type: none"> <li>• I appreciate you’re...</li> <li>• I’m grateful that you...</li> <li>• We’ve found...</li> <li>• From my/our experience...</li> <li>• For me/us...</li> <li>• Just so I’m clear on this, you want our opinion on...</li> <li>• In other words...</li> </ul>	<ul style="list-style-type: none"> <li>• My initial reaction is...</li> <li>• For me/us it would be helpful if...</li> <li>• Something I might consider...</li> <li>• The first idea I had was...</li> <li>• I see it differently...</li> <li>• I find myself resistant to the idea that...</li> </ul>
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**Effective Meeting Participation for Family Advisors**

**Ready to Speak Up: Different Ways to Participate and Give Input**

There are many different ways to give constructive input as a family advisor in a meeting. We’ve listed four levels of participation below:

**Level 1: Support and Affirm**

This is the most basic level of participation and input. It is an easy way to enter into a discussion and establish rapport. Be sure to stay sincere and genuine. Examples of giving support and affirmation include “I appreciate...”, “Thank you for...”, or “We value what you do”.

**Level 2: Offer Feedback**

This level of participation provides a chance for you to share your personal perspective on a situation or event. Some tips to successfully offering feedback include:

- Build on positive experiences whenever possible. For example: “We found things worked well when...”

- Be clear on whom you represent by pointing out that this is your story and not the story of all families and protecting others privacy.
- Lead in with soft start-ups. *For example: “For me...” or “I find it makes a difference when...”*
- Share a personal story in 30-seconds or less to help bring your feedback alive. Refer to next page as an example.
- If you are giving negative feedback, be specific and try to offer a potential solution. *For example: “What might have helped in that situation is...”*

### **Level 3: Offer Suggestions, Ideas and Potential Solutions**

A step beyond sharing your perspective is to offer suggestions, ideas, and potential solutions. For example: “Have you considered...”, “You might want to think about...”, or “What would have been great for us is...”

### **Level 4: Express Differing Viewpoints**

One of the more challenging ways of participating may be to express a different viewpoint. Your candid opinion can lead to greater understanding so tell yourself, “This is good. This is why I’m here”. Be sure to stay grounded and be respectful and describe your point of view in terms of your perception or opinion rather than a matter of fact or truth for all families. For example “I see it differently”, “I have a different priority”, or “That doesn’t work so well for us”.

## **Telling your story in 30 seconds or less**

Sharing personal experiences can be a very effective way to make your point. Stories work because they’re personal and their images stick with people in ways that abstract ideas or data don’t. Unlike a formal presentation, when you tell a personal story in a meeting, it must by necessity be brief. The temptation can be to include too many details because all of it really matters to you. In reality, if you offer too much detail, you will lose your listener. One very effective way to make your point is to bundle it in a 30-second anecdote.

Here are tips to creating an effective 30-second story:

1. Set the stage in the listener’s mind’s eye by giving just enough details to help paint the picture.
2. Tell what happened that illuminates your point.
3. Share what impact it had.
4. Some stories don’t need the point to be explained. Others might.
5. Remember less is usually better.

When it comes to sharing personal stories in a meeting setting, less is more. Here’s a 30-second anecdote one parent used to describe a positive experience with a doctor — in response to the question, “What matters to kids and their parents?”

*We came in for a routine check-back appointment. The doctor greeted me with a handshake, turned to my 13 year old and began talking. He never turned back to me that whole appointment. It was all between my son and the doctor. When we left the office, my son turned to me and said, "You know, Mom, I think that's the best doctor's appointment I've ever had." I agreed.*

- parent of a teen with special needs

## **What happens if you have a strong emotional response to the discussion?**

Family advising can tap into experiences that have been profoundly personal. A seemingly simple discussion may bring back memories that trigger a wave of strong emotion. Some describe this as being “flooded.”

Research tells us that when emotions set off this kind of strong reaction in your body, it is difficult to listen well and think clearly, let alone problem-solve creatively.

Ways to calm down and re-center yourself when you become flooded include:

- Begin by noticing it and naming it in your mind (*example: “This is interesting. I’m having a strong reaction to this topic”*).
- Remind yourself that this is common to the family advisor role.
- Be aware that your strong response indicates something about how important this issue is for you.
- Take a few deep, slow breathes. This kind of breathing assists in slowing down your heart rate and can be very grounding and calming.
- Sit back in your chair and just listen for awhile.
- Take notes.
- Stay present.
- Focus on the conversation.
- Speak up when you feel ready.