

# Becoming a Family Advocate Facilitator Guide and Curriculum

Center for Children with Special Needs, Seattle Children's Hospital  
Washington State Department of Health, Children with Special Health Care  
Needs Program

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## Becoming an Family Advocate

### ***General purpose of the training:***

This 3-hour training is a basic and foundational training for becoming a family advocate (also called advisor). It covers what it means to be family advocate; the different ways and settings in which one can advocate; and basic skills that will assist parents in their effectiveness as a family advocate. It offers information and skill building activities. Our goal is to affirm for caregivers the value and importance of skilled parent participation.

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**Training Outline:**

- 1. Welcome and Introduction**
  - A. Overview of agenda
  
- 2. Participant Introductions, Guidelines and Logistics**
  - A. Participants introduce themselves
  - B. Guidelines for group
  - C. Meeting logistics (breaks, bathroom, cell phones)
  
- 3. What is a Family Advocate**
  - A. Definition of family advocate
  - B. Types of things family advisors and advocates do
  - C. Why people want to become advocates
  - D. What is unique about the role
  - E. Continuum Exercise
  
- 4. Preparing to be an Advocate**
  - A. Questions to ask before saying “yes”
  - B. Questions to ask yourself
  - C. Saying no

**Break**

- 5. Three Dimensions of Effective Advocating**
  - A. Notice your reactions
  - B. Flooding
  - C. Listen to understand
  - D. Speaking up
  - E. Ladder of participation
  - F. Practice ladder skills activity
  
- 6. Training Review**

### Materials needed for the training

Set up the room to facilitate easy conversation and note taking.

You will need:

- Name tags
- Sign-in sheet
- Training folder at each place (with handouts and contact information of trainers)
- Pens
- Copy of the continuum worksheet for each participant
- Paper for Continuum-Exercise with numbers: #1, #5, #10 written in large print
- 2 flip charts if possible
- Pre-filled flip chart pages (see list on next page)
- Markers
- Way finding signs
- Light snacks and water
- Prepare a story for when you experienced a strong emotional reaction or “flooding” during an event or situation. This will be used in part 5.
- Envelopes containing multiple strips of paper listing each “ladder skill” for the ladder activity.
  - Support and affirm
  - Give feedback
  - Give feedback based on a negative experience
  - Offer suggestions
  - Express differing opinions

**Handouts:**

1. Definition of Family Advocate
2. Family Advocate Checklist
3. Continuum Activity
4. Tips for Effective Meeting Participation
5. Evaluation

### Flip Chart Pages

*Prepare the following flip chart pages ahead of time:*

1. Introductions:
  - Your name
  - Child's name, age, diagnosis
  - One thing you have learned about yourself since becoming a parent (or through your work with children and families with special needs if participants are not parents)
  
2. Agenda for today:
  - Get acquainted
  - Define family advocate
  - Preparing for family advocate experiences
  - How to become involved as an advocate and the skills you will need
  
3. Group Guidelines:
  - Speak for yourself
  - Listen well
  - Share the air time
  - Honor confidentiality
  
4. Fictitious scenarios where families have been asked to give input and feedback (*or provide examples of your own*)
  - Due to the budget shortfall your local school district is going to stop transporting preschool and elementary students to therapy appointments at different schools. Families will have to provide transportation to and from these services.
  - The local hospital is adopting and "no-co-sleeping policy" for children and parents.
  - The Department of Early Learning is considering a plan to make birth to three services center-based instead of home-based.
  - The school district is cutting funding for school nurses from 3 days to 1 day a week in elementary schools.
  - The State Legislature is voting on an act that improves financial support for family caregivers of people with disabilities or health conditions.
  
5. Three dimensions of effective advocating:
  - Checking in with yourself
  - Listening to understand
  - Speaking up
  
6. Ladder image for section 5.

*Note: There are various brainstorming activities throughout this training. It may be helpful to you to write a title on a few blank flip chart pages for these activities as a prompt for yourself.*

## Section 1: Welcome and Introduction 15 min

**Notes to leader:** Leader's tips are in *italics* throughout the curriculum. Adapt using your own words and experience etc.

### **Purpose:**

*This section introduces the training, gives participants an overview and sets context and tone. "Family Advocate" is the term we're using in this curriculum. It is broadly defined. Depending on your audience and what kind of organizations they will become involved with, the better term might be family advisor, family partner, family consultant or family leader. Use what term works best. For discussion and activities, find examples that are relevant for your group.*

### **Notes to leader:**

*Welcome attendees as they sign in and have them make name tags (table tent name cards work well). Invite them to fill in the "Continuum Exercise Sheet" as they wait for the training to begin.*

### **Materials your need for this section:**

- Flip chart and markers
- Pre-filled flip chart pages (family advocate definition & agenda)
- Continuum worksheet to be filled out while waiting
- Continuum numbers #1, #5, #10 on 8 ½ x 11 paper

### **Welcome participants**

- Welcome. We're excited to present our ideas to you in ways that we hope you'll find engaging and helpful.
- *Share some very brief introductory information about each of the leaders, such as names, background, current work, etc.*
- Everyone in the room has a child or works with families who have a child with a special need--this may include developmental, health, mental health or educational needs. Each of you comes with a valuable perspective that will add to the richness of our experience together today—whether you are new to the family advocate role or have had a fair amount of experience. We hope you see today as a time to gain understanding and insight about the family advocate role as well as skills to do it well.
- There are many different ways of thinking about what an advocate is, and everyone here has probably been an advocate at some time.
- You know your child and their world in ways no one else does. In that way you've become an expert on your own experience. It's this expertise that we'll be building on in today's training.
- One role that many parents and caregivers of children with special needs learn is becoming their child's advocate. This could include trying to make sure your child gets the support they need at school or making sure your doctor includes you and your child in making

decisions about health care and therapy. Many of us are also trying to teach our children to advocate for themselves – for example to speak up in class if they need something.

- Today we are going to focus on another kind of advocacy, which is when you go beyond your child and your family to try to make a difference to for all children and their families.
- Our definition of a family advocate is someone who shares their perspective and experiences to help schools, communities, healthcare organizations, early intervention programs, and government (just to name a few examples) to design and improve programs and services that will benefit all families. *Have this written up on flip chart paper.* (Please note, when we talk about being becoming a family advocate, we are using the term “advocate” in a general way. When people give input into governmental policies or laws this can also be called “advocacy” or “policy advocacy”. While this is an example of how someone can be an advocate, this is not the only kind of advocacy we are talking about )

***Give a brief overview of today's agenda (refer to pre-filled flip chart) Today we will:***

- Introduce ourselves
- Look at what it means to be a family advocate
- Offer you ways to prepare for your family advocate experiences
- Look at the different ways you can become an advocate and the skills you will need.

**Section 2: Introductions, Guidelines and Logistics -20 min**

**Notes to leader:** Begin by introducing yourself as a way to model a brief, concise introduction.

**Materials:** Pre-filled flip chart paper with 3 bullets: 1-Name, 2-Child's name, age and diagnosis (or a few words about their special needs), 3- One thing you have learned

**Introductions to one another**

- Let's start by sharing:
  - Your **name**
  - Your **child's name, age and diagnosis** or a few words about their special needs
  - As you think back on your experiences as a parent of this child, what's **one thing** you have learned about yourself?

*After introductions, continue as a group with hand raising, picking 4-5 of the following:* Now with a show of hands . . . Who has:

- Been in the hospital overnight?
  - Had a medical clinic visit?
  - Been in the emergency room?
  - Had your child evaluated by a specialist?
  - Looked for child care that will meet your child's needs?
  - Participated in an IEP or 504 planning process?
  - Met with an occupational, physical or speech and language therapist?
  - Talked with insurance representatives?
  - Applied for some governmental supported service?
- *End with an appreciation for the breadth of experience in the room: It's your experiences with all the organizations that you and your child interact with that form the basis for not only your involvement, but also your unique and valuable expertise as a family advocate.*

## Review Guidelines for Participating and Logistics

**Purpose:** *Establish shared understanding and expectations for the group.*

**Notes to leader:** *Important to be reviewed as they help set the tone(can be brief).*

**Materials:** *Flip chart with 4 bullets already written out.*

- We have structured our time together to make the best use of our time. So we ask for your help in keeping us on track.
- We encourage you to fully participate.
  - **Speak for yourself**
  - **Listen well**  
**Share the “air time”.** Our time is limited and we want everyone to have a chance to participate.
  - **Honor confidentiality.** What is said in this room should stay in this room.

**Logistics:** *Review bathroom locations, break times, cell phones to vibrate, contact number in the room, info about their folders, etc.*

**Section 3: What is a Family Advocate?****20 min**

**Purpose:** *The section delves into a deeper explanation of what it means to be a family advocate. It starts with a conceptual definition, gives examples and points out some of the unique dimensions to this kind of advising.*

**Notes to leader:** *This section has a lot of talking by the leader, keep it brief and pay attention to whether or not they're "with" you.*

**Materials you will need:**

1. flip chart
2. markers
3. handout: Family Advocate Definition

**What is a Family Advocate?**

In our training today we are going to use the term "family advocate" to describe this role but there are many other terms that would fit. These include "family advisor", "family leader", "family partner" etc. We use the terms "parents" and "caregivers" because we want to acknowledge that any family member can be a family advocate. Let's take a closer look at our definition of a family advocate.

- A family advocate is a parent or caregiver of a child or teen with special health, developmental or mental health needs. As advocates they work with organizations and government to make sure that child and family perspectives are integrated into programs, policies and practices.
- Family advocates **draw on their experiences and share their stories, perspectives, insight, observations, ideas and questions** in a variety of settings. This may include with staff from the government or an organization that works with families and children with special health needs.
- Advocates **help organizations understand families' perspectives and needs, shift people's thinking, influence decision-making and impact outcomes.**

You can see from our definition that becoming a family advocate involves a shift—from a personal agenda of what's good for "my child/our family" to what some call the "greater good" for all children and their families. There is a copy of this definition in your packet.

As we've mentioned there are many different ways to serve as family advocates.

*List a couple and then query the group for ways they've served or other ways of participating that they know of. Write up on flip chart paper.*

What kinds of opportunities have you had to participate in a group or be an advocate in the past? (At your child's school, church, community group, hospital, etc.)

- Serve on advisory groups
- Run support groups for other parents
- Participate in focus groups
- Write a letter to the school district or legislature about an issue
- Speak to groups about aspects of your experiences
- Serve on special needs PTA
- Participate in one-on-one interview to provide a parent perspective
- Review materials to see if they make sense
- Serve on committees
- Help write grant applications
- Write articles for newsletters
- Participate in legislative meetings or hearings
- Train other parents

#### **Discussion:**

As we can see there are many different ways to become involved as a family advocate.

What brings you to this training? Jot down a few words or phrases that describe why you want to become a family advocate.

*Facilitator asks parents to share some of their reasons. You can write them up on flip chart paper. If needed, you can supplement with these:*

- *An issue is important to them, their family and community*
- *They have something to contribute*
- *They believe they will be listened to, their contributions respected and their participation will make a difference.*
- *An opportunity to give back.*
- *To make it better for others*
- *To honor my child*
- *To bring meaning to my experience*
- *To join others*

We've listed some of the personal benefits that family advocates may experience from this kind of involvement. What do you see as the benefits for schools and hospitals and other groups who want families involved?

*Solicit suggestions and write them on flip chart: Benefits may include:*

- *Families put the human face on the issue*
- *Families are the users of the services—you are the best testing ground, understand the issues, live out the solutions.*
- *Family advocates bring real life to experience*
- *Family advocates have a perspective that organizations don't*
- *Families are able to translate ideas to what it might be like in reality—how will it work, what are its implications?*
- *Fresh perspectives and solutions. Most often the most practical and often most doable ideas come from families.*

### What's unique about this kind of work?

**Note to leaders:** *This is a brief mini-presentation. Write the key words up on the flip chart as you talk through it.*

#### **Materials you will need:**

1. *Definition of family advocate already written up on flip-chart/markers*

We're going to look at what is unique about this role for you.

- **Parent as expert.** You are here because you are a parent, as compared to doing this because it's your job or where you live, or because you are a member of a certain organization. You're here to share your experience and perspective.
- **What's been private goes public:** In this role you may need to share personal experience that you and your family have had
- **You move from the personal needs to working for the greater good.**
- **It's a shift in relationships.** In this role you may be working along side people who lead programs or provide services to your child. Examples could be your child's doctor, the principal of your child's school or a county or state service provider like the Developmental Disabilities Administration.

**Questions and comments?**

*Ask what questions there are about being a family advocate. Depending on their questions either briefly answer or defer to later in the training. You may want to make a list of their questions off to the side that you can refer to later to make sure you are covering everyone's questions.*

Now we are going to spend the rest of our time together on some of the skills and qualities that contribute to being an effective family advocate or advisor.

**Continuum Exercise****10 min**

**Purpose:** *This self-awareness exercise helps show the different styles and preferences that are in the group. It also gets people up and moving!*

**Notes to leader:** *Have participants fill this out ahead of time. It's meant to be fun and lively.*

**Materials needed:** *You will need:*

1. *Space in the room to do the exercise.*
2. *Completed forms*
3. *The numbers 1, 5, and 10 written on separate pieces of paper to set up the continuum on the floor.*

**Introducing the continuum activity**

- The vast majority of time you spend as a family advocate will most likely be in a group with others—sometimes with a group of parents, or you might be the only parent with a group of staff members.
- It can be helpful to know what works best for you and what you need to feel comfortable when you are in a group.
- *If attendees have not been able to fill out ahead of time:* Take a few minutes to answer the questions on the handout—which represent a range of ways people participate in groups. No right or wrong way. Don't overthink it. *Give people about 2 minutes to fill it in. Pay attention to when they are finishing. Give a heads-up about 30 seconds before the time is up*
- Let's take a look at our group and where people landed on the continuum. I've put numbers 1, 5, and 10 on the floor to reflect the continuum. Grab your paper and physically place yourselves along the continuum for as I read out different questions.

*With each question, have attendees spend a minute talking with the people close by about why they chose that number. Then facilitate a conversation with everyone. Ask some questions that help them explore the implications of the number they chose.*

- What is it that puts you where you are?
- What does this show what might work well for you in meetings?
- What might be challenging for you in meetings?

*After doing a couple, ask the group which ones they'd like to see. Start with # 10, # 3, or # 8. Time will determine how many you cover—usually 4-6.*

## Closing the Activity

Everyone has preferences about ways to be in groups. We saw it with our group just now—some prefer to speak after thinking things through, some think out loud, some need the details and others like the big picture.

It takes all of us to make a strong team. Most groups need the listener and talkers, the detail-focused and the big picture thinkers. The more you know and understand about yourself—what makes you comfortable or uncomfortable — the better you are able to get what you need to feel confident and draw on your experiences effectively to influence change.

For example, if you're a person who does better with time to consider and think something through, then asking for information ahead of time could help you to feel more effective in contributing. If you are a person that likes the big picture, you may want to ask someone to describe the overall purpose of a meeting prior to starting.

**Section 4: Preparing to be an advocate****10 min**

**Purpose:** Family advocacy works best when advocacy activities are a “good fit” for the parent or caregiver as it relates to the subject matter, the time in your life, the design of event, logistics of time and place etc. This section reinforces the importance of knowing what is being asked of the parent or caregiver so that they can make an informed decision about whether or not to take part.

**Notes to leader:** You will ask participants to think about what questions they would have when being asked to take part in an event or situation for being a family advocate.

**Materials:** Questions handout found in training folder

**Questions to ask before saying yes**

Imagine you just received a call from your local Parent to Parent coordinator who wants to know if you would like to be on a parent panel for the local community college. They are having parents of children with special needs talk about their experiences to students in the early education program.

What questions do you all think would help you prepare for this event? *Have the group brainstorm questions. List them on the flip chart paper. Add the questions below if they have not been mentioned.*

1. What’s the purpose of the meeting/event?
2. What kind of input are you looking for from parents?
3. When will it be happening?
4. What’s the format of the meeting?
5. How long is the meeting?
6. Where will it be taking place?
7. Who’s going to be there?
8. What other parents will be there?
9. What’s important for me to know about this group?
10. What is my role?

These are on a handout.

Once you have this information, it's important to take some time to ask yourself some questions.

### Questions to ask yourself

Ask the group what questions they may want to ask themselves? (Prompt if needed). List their responses on the flip chart paper and supplement with these questions if not mentioned.

1. Do I have the time for this?
2. Am I at a place in my life that this will work for me?
3. Do I want to do this?
4. What is my experience with the topic?
5. What do I need to feel prepared?
6. What support or help will I need to be able to attend? (Transportation? Childcare?)

### If you decide to say "yes" then these questions can help you prepare:

1. How can I prepare for the meeting?
2. What will be the focus of the meeting?
3. What's the goal of the meeting?
4. What terminology do I need defined? (Some organizations use acronyms or terms that are not common).
5. Who is my contact?
6. What should I wear?
7. What is the meeting room number?
8. Where do I park?
9. How long is the meeting?
10. Is there a stipend or a payment to cover my costs?

These are also in your packet. We've learned that when family advocate experiences are a "good fit," people find it satisfying and are usually successful. Knowing yourself and your life situation will help you decide if it's the "right fit." If you decide that you can't participate or you don't want to or don't think it's the right fit for you, it's important to honor that and not fear you'll offend or never be asked again. What are some effective ways to say "no" that works for you? Examples might include:

- *Thanks so much for thinking of me, but right now, that doesn't work for me.*
- *I'm so sorry but my plate is too full right now.*
- *I don't think I have the kind of experience you are looking for.*
- *I need to focus on my child and family's needs right now.*
- *Others?*

*Support and affirm people's suggestions. Emphasize the importance of knowing your limits and how you can briefly and graciously decline an invitation.*

**Break**

**10 min**

**Section 5: Three Dimensions of Effectively Advocating****20 min**

**Purpose:** *This section covers 3 dimensions of effective advocating:*

- *Checking in with yourself*
- *Listening to understand*
- *Speaking up*

**Notes to leader:** *During this segment you will discuss:*

- *Noticing your reactions*
- *The concept of flooding*
- *Thinking together about strategies for managing strong emotional reactions*

**Materials:** *flip chart, markers, pre-written flip chart paper with 3 dimensions of effective advocating and examples of family advocacy topics*

**Dimension 1: Notice your reactions.**

- Being aware of your reactions is an important part of this work. Let's look at some topics where you might get involved as a family advocate.
- I'm going to list a few and ask to you write down your first reactions to a couple of questions.

*Have this list written up as a list ahead of time on flip chart paper (these are made up; add more of your own examples)*

- Due to the budget shortfall your local school district is going to stop transporting preschool and elementary students to therapy appointments at different schools. Families will have to provide transportation to and from these services.
- The local hospital is adopting and "no-co-sleeping policy" for children and parents.
- The Department of Early Learning is considering a plan to make birth to three services center-based instead of home-based.
- The school district is cutting funding for school nurses from 3 days to 1 day a week in elementary schools.
- The State Legislature is voting on an act that improves financial support for family caregivers of people with disabilities or health conditions.

*The purpose of this exercise is to make the content of family advocacy come alive for participants and to see how emotionally charged some topics can be.*

Some of these topics may have generated strong responses, while others were more neutral.

- Which one of these stirred the strongest response in you?
- Let's look at # \_\_. What were some of your first thoughts? Feelings? *Encourage people to call them out. Encourage others through a neutral response, such as "thanks, what about others?" Who else?*

*Ask for their reactions. Summarize by restating a variety of reactions that people can have.*

In general, we've learned that there are few neutral or casual topics for those in the family advocate role. What might be seemingly straightforward topics to some people can stir strong reactions because you've lived them—you care about the outcome.

So, being aware of and managing your reactions is critical. It helps you bring up questions that contribute to a productive conversation, share feedback in helpful ways, and learn when it's best to wait before participating, particularly if you're upset.

## Flooding

**Materials:** *Paper and pens for all participants*

Sometimes the topic you're discussing has caused you to have a strong reaction. You get a wave of stress signs—like sweaty palms or feeling warm, increased heart rate, muscle tension and faster breathing.

The term for this kind of experience is becoming flooded. This wave of stress interferes with:

- Listening
- Thinking
- Communicating
- Problem-solving

Flooding gets in the way of productive discussions. Creative thinking, empathy, and even humor disappear. When you're held in the grip of this intense response it's tough to hold back your responses. To get back on the road to effective communication and constructive discussions, we need to settle ourselves, calm our response.

Can you think of a time when you've had that kind of strong reaction concerning your child? Perhaps it was a school meeting, talking with a therapist, doctor or family member?

Write down a few key words that will help you remember the experience.

- Where were you?
- What set off your strong feelings?
- How did you experience the flooding? Where in your body did you feel it?

*This concept is best understood if you have an example of when you have experienced flooding. Describe the triggering event, what it felt like during and after. After sharing this, ask for other examples from the group.*

*In large group:* In general, what were some things that can cause flooding? What did it feel like for you? *Respond to participants with something like, "thanks" or "yes" and "who else?" Your goal is to get ideas out—no need to comment on them.*

Let's assume you're worked up, and aren't able to do your best thinking and listening, **what are ways you can calm yourself in order to listen and focus better?**

*Examples include:*

- *Breathing—consciously taking slow deep breaths to help bring your heart rate down*
- *Pause*
- *Physically leave—take a "bathroom break"*

- *Note taking*
- *Naming how you are feeling “This is making me sad/upset/angry.” “This is bringing back so many of my memories—scary ones.” Or simply, “flooding.”*
- *Talk to yourself. “Since I’m flooded, this is NOT the right time for me to speak up. I need to step back just a bit before I act on this.”*
- *Be quiet for a while and just listen to others*
- *Stay present and open to the flow of the conversation*
- *Others?*

**Ending this section:**

Thank you. We’ve identified not only why family advocacy conversations cause strong feelings but we have also come up with ways to manage these reactions.

**Dimension #2: Listen to understand. 10 min**

**Purpose:** *It is important to listen to understand and ask clarifying questions before sharing your perspective.*

**Materials:** *flip chart*

**Listening**

Dimension #2 is all about listening to others.

As a family advocate you will be asked to give feedback and your perspective. But before you do, it is important to make sure you understand:

- The scope of topic
- What they are asking of you
- How you can add to the discussion

**Listening to understand**

Asking questions can help you understand what is being asked of you

Here's a very simple example: Let's say that I called you up and asked if you would give me feedback about this training.

What kind of questions could you ask to get clearer about what kind of feedback I'm asking for?" *Query group. No need to write up.*

- *I'm not quite sure I understand the specific part of the training you want me to respond to; can you clarify that for me?*
- *What kind of feedback would be most helpful to you?*

And, as I answer your questions you might try summarizing:

- *So, you want our feedback on. . . .*
- *Let me make sure I understand you correctly*

**Jargon:** There's lots of jargon in most organizations. Ask that jargon be explain in plain language even if you feel like everyone else in the room knows what they're talking about. Chances are good that others don't understand either.

**Ask questions judiciously.** Guard against following your own interests, fascination, fears, and tangential topics.

**Follow the flow of the group conversation.** *Query the group:* What helps you stay focused in a meeting? *Examples include:*

- Notetaking

- Advanced preparation
- Coming rested

*Ask for questions and comments from the group about listening.*

**Summarizing comments:** *reinforce the importance of good listening and how it can be challenging in family advocacy.*

**Dimension #3: Speak Up****25 min**

**Purpose:** The ladder of participation illustrates the different ways to provide constructive input. Going from easy to more difficult.

**Notes to leader:** Begin at the bottom rung of the ladder and move up from there. On each rung, write in the key word bolded below, highlighting the 4 primary ways.

**Materials:** Flipchart and markers, Ladder of Participation already drawn on flip chart

**4 Primary ways of speaking up**

There are many different ways to give constructive input and share your perspective. We are using the image of a ladder to demonstrate that speaking up starts out easy and gets more difficult. The ways of speaking up include:

1. Support and affirm (*bottom rung on ladder*)
2. Offer feedback
3. Offer suggestions
4. Give a different viewpoint (*top rung on ladder*)

**1. Support and affirm (2 minutes)**

We're going to start at the bottom of the rung of the ladder:

- This is a positive response that affirms the other.
- It's an easy way to establish rapport.
  - *I appreciate . . .thanks. . .good job*
- It should be sincere, genuine
- It's a good starting place for whatever follows.

## 2. Offer feedback 8 min

The next step up the ladder is offering feedback. This is giving your personal perspective on what you think, how it feels, what's confusing, etc. Here are a couple of tips:

- **Build on the positive:** whenever possible you want to start with what has worked well for you. This helps the listener stay open to hearing what you have to say vs. getting defensive. *A brief example from the leader contrasting the impact of approaching it negatively vs positively works well here.*
- **Soft start-ups:** This is starting a problem or challenging topics with softened language. This helps the listener stay open and, increases your chances of being heard. This is opposed to a harsh or "on the offense" start that can come off as critical and blaming. These can cause someone to feel defensive or guarded.

These are some soft start phrases that can be effective:

*List on flip chart*

- *I find myself thinking. . .*
- *For me. . .*
- *We've found. . . .*
- *For us. . . .*

## Giving Negative feedback -5 min

**Purpose:** *Provide examples of negative feedback. Use brainstorming with the group to come up with how to provide negative feedback. Be ready to provide tips for giving negative feedback so that it can be heard.*

**Notes to leader:** *Often it is a family's negative experiences that form the basis for their feedback*

There will be times when your feedback will be about experiences when things didn't go well. How do you make that work? Has anyone had an experience when this worked well?

### 3. Offer suggestions, ideas and generate solutions 5 min

**Materials you will need:**

1. *Soft start-up list from previous activity*
2. *marker*

Let's imagine that you're sitting in a meeting and you know that you'll be asked for suggestions.

- Pay attention to ideas that you have. The feedback we hear from organizations that invite families to participate is that parents come with practical ideas that staff haven't considered.
- What's obvious to you isn't obvious to others.
- This is another time when soft start-ups are a good strategy. What have you said to introduce an idea in situations in the past when you want the other person to be receptive to your ideas? *Give some example and continue to build list on flipchart as participants give examples.*
  - *You might want to think about...*
  - *Have you ever considered?*
  - *For me/us it would be helpful if...*
  - *The first thing that comes up for me...*
  - *I remember when someone. . .*
  - *Last time us. ... it was so helpful when*

### 4. Express different viewpoint 5 min

**Notes to leader:** *This is the highest rung of the ladder that we're going to cover in this session. It is a response that requires the skills and the right kind of group climate to share differences of opinion or perspective. It's important to emphasize the importance and value of diverse viewpoints, and that there is not one parent perspective. Also, you will want to emphasize that family advocates grow in their confidence to speak up effectively.*

Our top step of the ladder today is expressing a different viewpoint.

Here are some tips for expressing a differing viewpoint. *(You may want to have this written on the flip chart ahead of time.)*

- Describe the problem in terms of your perception, opinion or style vs. describing the problem as the only way or the truth

- *Brainstorm lead-in phrases - give some example and continue to build list on flipchart as participants give examples.*
  - *I see it differently...*
  - *Our experience was very different from yours...*
  - *I feel uncomfortable/unsure about....*
  - *I have a different priority...*

One final note: no matter whether you are offering feedback, positive or negative, suggesting ideas or expressing differing viewpoints, sharing brief 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.

As you know from your experiences at doctor's appointments and school meetings, it's a fast-paced environment and there's always another meeting that people need to get to. So you may find that people aren't interested in lengthy explanations or details. They want you to get to the point. It is always best to be prepared and 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.

**Practice Ladder Skills Activity****10 min**

**Purpose:** *practice speaking up skills and for you to provide coaching and feedback.*

**Notes to Leader:** *Briefly review the ladder steps. Have group count off into teams of two.*

**Materials you will need:**

1. *Soft start-up list from previous activity*
2. *Ladder of participation graphic and topics list*

*Explain that each pair will practice giving feedback on one of the topics on the list. Each person in the pair will get a chance to practice. You will give each team one of the types of feedback to practice (leave out the “support and affirm” type of feedback because this is the easiest). Give each pair one of these three:*

- *Offer positive or negative feedback*
- *Offer a suggestion*
- *Give a different viewpoint*

*Next, each pair chooses which topic to discuss from the list on the flip chart.*

*Provide topics that you know people will have an opinion on and that is relevant to participants.*

*Here are suggestions (some real, some fictitious):*

- *Due to the budget cuts the local school district is going to stop transporting preschool and elementary students to therapy appointments at different schools. Families will have to provide transportation.*
- *The local hospital is adopting and “no-co-sleeping policy” for children and parents.*
- *The Department of Early Learning is considering a plan to make birth to three services center-based instead of home-based.*
- *The school district is cutting funding for school nurses from 3 days to 1 day a week in elementary schools.*
- *The State Legislature is voting on an act that improves financial support for family caregivers of people with disabilities or health conditions.*

*The first person practices while their partner listens. Then the partner gives feedback on how they did. The partner should address:*

- *What was their communication effective? What worked well?*
- *What could be done differently or what other strategies could be used to make the point?*

*Give the pairs about 1-2 minutes for the first person to practice and get feedback and then another 1-2 minutes for the second person to practice.*

*After the teams have practiced, ask for volunteer pairs to come up and show their feedback. Use this as a way to provide positive support and coaching for the teams. Ask those watching if they*

*have constructive feedback or suggestions for the volunteers. You may have time for 1-2 pairs to come up and model their feedback skills.*

*Debrief: How did that go? What was easy/natural? What was harder? Questions? Comments? Coaching tips?*

*Summary: Comment about how becoming an advocate is something where you grow continuously with every experience that you have. The more you participate as a family advocate, the more comfortable you will become with these skills/activities/approaches.*

**Section 6: The training in review:****5 min**

**Purpose:** Review of all that's been covered.

**Notes to Leader:** Affirm their participation, concentration and attention!

**Materials you will need:**

1. Training in review list
2. Evaluation forms

As we wind things up today I want to thank you so much for your focused attention and concentration. We've covered a lot and it's a lot to take in!

- We looked closely at being a family advocate
  - Defining the role of a family advocate
  - Why people get involved
  - What's unique about it
- Self-Awareness
- Questions to ensure a particular opportunity is the right fit for you
- Strong reactions and flooding
- Strategies for managing strong reactions
- 3 Dimensions
  - Tuning in/listening to yourself
  - Listening to understand
  - Speaking up
    - Support and affirm
    - Give positive and negative feedback
    - Use soft start-ups
    - Offer suggestions and generate solutions
    - Offer differing viewpoints

To close our meeting, let's go around the group and briefly share one thing you want to take with you from today's experience—an insight, a tool, a highlight.

*Leaders conclude the sharing.*

Again, thanks for your part in making this a rich experience for all of us.

Good luck with your future advocacy opportunities. When you have the opportunity to participate in advocacy, we encourage you to connect with the person who invited you to the event or meeting after you have been an advocate—for support, with questions, feedback and for problem-solving. Please take a few moments to fill out the evaluation and put them in the envelope. We take your feedback seriously and use it to help improve our trainings.

# Handouts

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Center for Children  
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**Becoming a Family Advocate  
Where do I land?**

1. I think fast on my feet \_\_\_\_\_ Need to mull things over

1      2      3      4      5      6      7      8      9      10

2. Avoid Conflict \_\_\_\_\_ Seek Conflict

1      2      3      4      5      6      7      8      9      10

3. I like details \_\_\_\_\_ Like to know the big picture

1      2      3      4      5      6      7      8      9      10

4. I speak to think \_\_\_\_\_ Need to think before I speak

1      2      3      4      5      6      7      8      9      10

5. Thrive in groups \_\_\_\_\_ Do my best working alone

1      2      3      4      5      6      7      8      9      10

6. Love problem solving \_\_\_\_\_ Problem solving tedious or overwhelming

1      2      3      4      5      6      7      8      9      10

7. Need to have things spelled out in black and white \_\_\_\_\_ I like to think about concepts and ideas

1      2      3      4      5      6      7      8      9      10

8. Listener \_\_\_\_\_ Talker

1      2      3      4      5      6      7      8      9      10

9. Open \_\_\_\_\_ Private

1      2      3      4      5      6      7      8      9      10

10. Jump right into the discussion \_\_\_\_\_ Hold back

1      2      3      4      5      6      7      8      9      10

## Family Advocate

A family advocate is a parent or caregiver of a child or teen with special health, developmental or mental health needs. They work with organizations and government to make sure that child and family perspectives are integrated into programs, policies and practices.

Family advocates **draw on their experiences and share their stories, perspectives, insight, observations, ideas and questions in** a variety of settings with staff from the government or an organization that works with families and children with special health needs.

## Family Advocate Checklist

There are several things that will help be able to answer yes or no to an invitation to give your input or feedback. Here are some questions that you might ask an individual or organization that requests your involvement:

1. What's the purpose of the meeting/event?
2. What kind of input are they looking for from parents?
3. When will it be happening?
4. What's the format of the meeting?
5. How long is the meeting?
6. Where will it be taking place?
7. Who's going to be there?
8. What other parents will be there?
9. What's important for me to know about this group?
10. What kinds of things should I prepare or think about beforehand?
11. What is my role?
12. Is there a stipend or payment to cover my costs?

Once you have this information you can ask yourself some questions.

### Questions to ask yourself

7. Do I have the time for this?
8. Am I at a place in my life that this will work for me?
9. Do I want to do this?
10. What is my experience with the topic?
11. What do I need to feel prepared?

### If you decide to say yes, then these questions may help you feel prepared

11. How can I prepare for the meeting?
12. What will be the focus of the meeting?
13. What's the goal of the meeting?
14. What terminology do I need defined? (Some organizations use acronyms or terms that are not common).
15. Who is my contact?
16. What should I wear?
17. What is the meeting room number?
18. Where do I park?

### After the meeting or activity:

Connect with the person who invited you to the event or meeting. Check in with them and let them know how it went and any issues that came up or questions you had.

## Effective Meeting Participation

As a family advocate, you will bring valuable information and ideas to a discussion. Listening well, asking thoughtful questions and how you communicate will go a long way to helping your input be well received and on target. Tips for effective meeting participation include:

### 1. Prior to the meeting learn and understand what you are being asked to do:

- Be certain you understand the focus of the meeting
- Make sure you are clear what you are being asked to comment on

### 2. 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 DDA means. Would you please explain it?"*)
- Ask for more details

### 3. Think before you speak

Starting your comments in a gentle, soft tone can be an effective way to increase your chances of being heard by others.

Examples of soft start ups include:

- I appreciate...
- I'm grateful that you...
- We've found...
- From my experience...
- My initial reaction is...
- For me/us it would be helpful if...
- Something I might consider...
- The first idea I had was...
- I see it differently...

## Different Ways to Participate and Give Input

There are many different ways to give constructive input in a meeting.

### 1. Support and Affirm

This is the most basic level of participation and input.

Examples of giving support and affirmation include:

- "I appreciate..."
- "Thank you for..."
- "We value what you do"

### 2. Offer Feedback

This provides a chance for you to share your personal perspective on a situation or event.

- When possible, build on positive experiences. 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.

### 3. Share a personal story

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..."

### 4. Offer Suggestions, Ideas and Potential Solutions

For example:

- "Have you considered..."
- "You might want to think about..."
- "What would have been great for us is..."

### 5. Express Differing Viewpoints

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"

The Department of Health and Seattle Children’s Center for Children with Special Needs designed this training to support parents and caregivers of children with special needs who would like to participate in advocacy activities to share the perspective of families of children with special needs.

Your feedback on this anonymous survey will help us improve the training for future participants. We ask questions about your background because our goal is to provide training to parents and caregivers of different ages, backgrounds and levels of advocacy experience.

1. Please share how much you agree or disagree with these statements. *(For each statement, circle the number that best describes your opinion.)*

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
I understand what a family advocate does.	1	2	3	4
I have tools to help me decide whether or not I want to take part in an advocacy activity.	1	2	3	4
I have tools to help me calm down if I have a strong emotional reaction while taking part in an advocacy activity.	1	2	3	4
I have tools to provide a suggestion in a way that will help others be open to my ideas.	1	2	3	4
I have tools to help me participate when I have a different opinion from others in the room.	1	2	3	4
I have tools to provide negative feedback in a way that will help others be open to my ideas.	1	2	3	4

2. Please share how much you agree or disagree with these statements about today’s training. *(Circle one number for each statement.)*

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
I felt comfortable sharing ideas.	1	2	3	4
I felt comfortable asking questions.	1	2	3	4
The group had open discussions about the material.	1	2	3	4
The information provided was useful to me.	1	2	3	4

4. What was the best part of the training?

4. What suggestions do you have for improving the training?

5. What other leadership training topics are of interest to you? *(Please check all that apply.)*

- Advocating with your story
- Facilitating supportive conversations
- Advocating with local or state government
- Working collaboratively in teams
- Building partnerships or coalitions
- Leading an effective meeting
- Negotiation
- Managing conflict
- Discovering your advocacy skills and strengths
- Developing advocacy strategies to address community issues
- Understanding different styles of learning, working and leading
- Other: \_\_\_\_\_

6. Have you ever participated in advocacy activities (eg. meetings, committees) where you were representing the perspective of families of children with special needs in general (**excluding** activities for your own child, like your child's Individualized Education Program [IEP] meeting or doctor's appointment)?

- Yes
- No → Go to question 8



7. **If Yes:** How many times have you participated in this kind of advocacy activity in the past year?

- 1 time
- 2-5 times
- More than 5 times

8. Is it likely you will participate in advocacy events, meetings, or activities in the future?

- Yes, very likely
- Yes, somewhat likely
- No, not very likely
- No, not at all likely

9. What is your relationship to a child with a special need?

- Mother
- Father
- Other family member
- Other

10. How old are you?

- 18 to 25
- 25 to 35
- 35 to 45
- 45 to 55
- 55 or older

11. What is your race/ethnicity? *(Please check all that apply.)*

- African American/Black
- Asian
- Pacific Islander
- Latino/Hispanic
- Native American
- Native Alaskan
- Caucasian/White
- Prefer not to identify
- Other: \_\_\_\_\_

12. What is the highest level of education you have completed?

- Junior high
- High school
- Some college
- College
- Graduate degree