

# Skills for Effective Parent Advocacy

## Trainer's Manual



**A Curriculum by the National Family Advocacy  
Support and Training (FAST) Project**

**FAST is a project of PACER Center.**

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## **Skills for Effective Parent Advocacy**

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# Introduction for Trainer

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Every parent wants to see their child be happy, healthy, and part of their community. Oftentimes, however, parents need to advocate to get their child the services they need. This curriculum was developed to help parents be an effective advocate for their child. While professionals have knowledge in a certain area, parents have a life-long relationship with their child and they are the “expert” on their child.

This curriculum will explore what it means to be an advocate and the skills that are needed to be effective.

**Intended Audience:** The intended audience for this training is parents of children with disabilities, who are from racial, ethnic, or cultural minority backgrounds, poor, geographically underserved or otherwise underserved or underrepresented.

**Purpose and Goal of Training:** The goal of this presentation is to empower parents so they can become effective advocates for their children and receive the services their child needs. This will be achieved by providing information and an opportunity to practice skills in a supportive environment. Advocacy is a skill best practiced, but many parents need a solid foundation to start with. This foundation is composed of the key knowledge areas of: understanding their child’s disability, knowing the key players, knowing their rights and responsibilities, being well organized, using clear and effective communication, and knowing how to resolve disagreements.

This presentation also includes information on resources that parents may find helpful.

## **Workshop Objectives:**

1. Parents will understand what “advocacy” means.
2. Parents will learn the skills necessary to be an effective advocate.
3. Parents will have an opportunity to practice key skills for being an effective advocate.
4. Parents will know what additional resources they may need and where to go for more information.

## **Supplies Needed for This Training:**

1. 5” x 7” note cards and pens for participants to write questions that they might feel uncomfortable asking out loud. These should be placed throughout the room within easy reach of participants.
2. Easel and easel paper or whiteboard to record input from participants during interactive portions of training.
3. Copies of the handouts that accompany the presentation: “Introducing Your Child to the School Community Using a “Student Snapshot” Format,” “Communicating about Services for your Child,” “Attending Meetings to Plan Your Child’s Individualized Education Program,” and “How Can My Child Be Involved in the IEP Process?”
4. Copies of the presentation.

**Evaluations:** Participant evaluations are important component of any training. Please distribute and collect evaluation forms from all workshop participants. They can be found in the appendix.

**References:** This curriculum is based on extensive review of the literature, as well as existing training tools and education materials on advocacy for youth with disabilities.

## Tips for Trainers

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You are the key to making this training a success. Knowing your community and bringing your own experience and stories will make the curriculum engaging and relevant for families. This curriculum is based on extensive review of the literature, as well as existing training tools and education materials designed to provide core topical information based in research and best practice. National focus groups and pilots by Parent Centers have been conducted to ensure the content is useful to families of children with disabilities who are underserved or underrepresented.

### Tips

1. PowerPoint Slides—PowerPoint slides are left open for you to edit and revise as you feel necessary to engage your community. This includes eliminating or adding slides, and using different wording or images.
2. Preparing to Present—Information is provided on each slide as a way to prepare your own remarks and examples during the session. Presenters' notes are not meant to be a script for the session. Feel free to organize these notes in any way that is helpful including adding your own notes.
3. Activities, Stories and Examples—Use “Related Activities” as a way to structure your own activities for families. Activities, stories, and examples allow families to better relate information to their own lives and understand how they can apply what they are learning.
4. Information Packets—Use “Related Resources” and handouts found in the appendix of this curriculum as a starting point for creating information packets for families. Add your own handouts and information on local resources. Information packets should include:
  - Flyer on FAST Web site
  - FAST Evaluation Form (*to be conducted at the end of the training*)
5. Translations—Spanish translations are provided of the PowerPoint, FAST evaluation, and handouts for this curriculum. The PowerPoint is left open for you to edit and revise as you feel necessary to engage your community. This includes eliminating or adding slides, and using different wording or images. If you would like to make edits to any of the accompanying handouts, please contact FAST at PACER and we will send you the handout in a Word Document that can be edited.

### Specific to this Curriculum

This curriculum is intended to be delivered to parents of youth with all types of disabilities. The goal is for parents to learn advocacy skills and strategies that they can use in many different situations with a variety of agencies and systems of care or service.

Advocacy is simply speaking up for yourself or others. Most of us do this every day without realizing it. Trainers can encourage parents to realize that with new skills and strategies, they can be more effective and intentional advocates for their children with disabilities. If an audience seems to be more interested in a particular system such as education or social security, then more examples from that system will help parents see a link to how they can actually use the information to make a difference in the life of their child with a disability.

## Slide 1: Title Page

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# Skills for Effective Parent Advocacy

A curriculum created by the National Family Advocacy Support and Training (FAST) Project, a project of PACER Center: [fastfamilysupport.org](http://fastfamilysupport.org)

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## Slide 2: Workshop Information

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Workshop presenters may wish to insert Parent Center name, location, and date of workshop, and names of presenters on this slide.

### Skills for Effective Parent Advocacy

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## Slide 3: Agenda

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Today we will talk about advocacy, which is speaking up for yourself and others. We'll also learn about the skills you need to be an effective advocate. In addition, we'll talk about specific ways you can make a difference.

Our hope is that you will find one or more skills you can use to become a more effective advocate for your child with a disability. Recently in a workshop like this one, a mother whose child is blind and has cognitive disabilities stood up during the training and said, "I have always been a private and shy person. I never liked to speak up, but I am learning today that I have to speak up if life is going to work for my son and family."

## Agenda

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**You will learn:**

- What advocacy means
- How to improve your advocacy skills
- How you can make a difference!

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## Slide 4: Use Your Power

### Use Your Power

**“The most common way people give up their power is by thinking they don’t have any.”**

—Alice Walker

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Parents of children with disabilities who participated in recent focus groups expressed a lot of frustration.

- I feel like my child’s teacher thinks she knows my son better than I do.
- It seems like the staff members support their system and not me and my child.
- I always feel spoken down to.
- When I ask for clarification, I feel ‘brushed off’ or rushed along. This makes me feel voiceless.
- Sometimes I just give up and leave it to the school.

- I get the attitude that “we are the professionals; we know what’s best so just listen to us.”
- I do not understand if they are telling me the truth. I’m not in a position to question anything.
- I only seem to get the services my child deserves when I know my rights and responsibilities.

#### RELATED ACTIVITY

Ask: Do you feel any of these frustrations? Others you’d like to share? After they share, ask parents what they think the above quote means.

The goal of this workshop is to help you realize that you DO have power and can be an effective advocate for your child. We will help you learn more skills to do this.

All of your children may need you to advocate for them at different times and places in their lives, but your child with a disability may need more help for a longer time. You may not find it easy to be an advocate, but it’s very important and you CAN do it! In fact, YOU are often the ONLY one who can!

You don’t need to feel frustrated or powerless about your child’s issues. You can use the power you have for effective advocacy for your child with a disability.

## What is an Advocate?

**Advocates speak up for themselves or others to make things better.**

### Have you ever?

- Met with your child's teacher about any issue?
- Spoke at a local gathering about a project you care about?
- Told a cashier that an item was not ringing up correctly?

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## Slide 5: What is an Advocate?

An "advocate" can be broadly defined as "someone who speaks up to make things better." Advocates can speak up for themselves or others.

Each of you has already been an advocate. You may not have attached that label to your actions. Advocacy covers a very broad range of activities that just about everyone, in many settings, does everyday. You advocate for yourselves and you advocate for others.

As a parent of a child with a disability, you have already had to speak on behalf of your child. You may have spoken to a teacher, day care worker, doctor, nurse, social worker, other parents, relatives, or friends.

### Related Activity

Ask participants to raise their hands if they have advocated during the past year for their child with a disability. Ask: would any of you share where you have already advocated for your child?

## Why be an Advocate?



- Your experiences are valuable and can be used to improve things
- You know when something is or isn't working
- You have ideas how to make things better
- You have the only long-term connection to this child

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## Slide 6: Why be an Advocate?

Parents bring their own valuable experience with their child to the table. Parents are the experts about their child.

Professionals have knowledge and expertise in a specific area, but they are only a temporary part of your child's life. Professionals will pass in and out of your child's life, but you will always be the parent.

Professionals deal with many children, but you only have your child to think about. A child is served best if parents and professionals work together.

However, your child will need you to advocate for him or her. NO ONE cares about your child as

much as you do, but you must speak up to make sure that your child becomes as independent, productive, and happy as he or she can be. As a parent, you want your child to belong and participate in the community where he or she lives. Only you can make that happen; no one else can.

## Six Skills

### To be an effective advocate:

1. Understand your child's disability
2. Know the key players
3. Know your rights and responsibilities
4. Become well organized
5. Use clear and effective communication
6. Know how to resolve disagreements

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## Slide 7: Six Skills

What does it mean to be an “advocate”?

An advocate is a: supporter, backer, believer, and promoter. You can be all of these!!

You undoubtedly already have many skills in the six skill areas listed here. The goal of this workshop is to expand your skills so that you can become a more effective advocate for your child. This workshop will give an overview of these important advocacy skills and will also provide resources to learn more.

Looking at this list, ask yourself, “Which is my strongest area? Weakest? In which areas could I learn more so I can be more effective?”

## In Other Words:

1. Who is the “star”?
2. Who are the players?
3. What are the rules?
4. What is my plan of action?
5. What do I say when it's my turn?
6. What do we do when we disagree?



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## Slide 8: In Other Words

Advocacy is much more important than playing a game for recreation, but some of the main ideas are the same.

Imagine you are playing a board game or a card game. Games have rules, and the players need to know those rules to play the game. But the players also need “people skills,” such as turn-taking, concentration, making conversation, and managing emotions (do you play with a “straight face”?). What is the strategy or plan you will use in the game?

Of course, the social security program, your doctor's office, and your child's special education program are not “games,” but they have processes

with “rules” that also require “people skills” and the skill to resolve a disagreement. Knowing the rules of the “game” or process will help you be an effective advocate for your child.

## Skill #1: Understand Your Child's Disability



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### Understanding helps you:

- Know which services are appropriate for your child
- Have high expectations
- Find the right assistive technology and accommodations

### Use resources to learn more!

## Slide 9: Skill #1: Understand Your Child's Disability

Why is this important? Understanding your child's disability:

- Helps you understand the options for raising a child with this disability
- Helps you ask educated, informed questions
- Helps you understand if the services are appropriate to meet the needs of your child

### High Expectations

#### PRESENTER NOTES

Ask parents what "high expectations" means to them. Ask for specific examples of what their

expectations are for their child.

- Expect that you will become a more effective advocate for your child
- Expect that your child will participate in his or her own success
- Expect that the schools, agencies, doctors, legislators, and others will partner with you

**Assistive Technology (AT) and accommodations** are often a key to learning and to accessing services.

- Learn which specific assistive technologies or accommodations can help your child. Are there AT methods or accommodations that help other children who have the same disability as your child?
- Learn that assistive technology includes a large variety of helpful tools, such as computers, voice simulators, hearing aids or FM systems, Braille, curb cuts, elevators, captions, note takers, and more. The list is endless!
- Learn to use the word "access." What will it take for my child to access (be able to use, benefit from) this service or activity? For example, a person who is deaf may need a sign language interpreter, a person who uses a wheelchair may need an elevator or curb cut, or a person with a cognitive delay may need directions simplified.

#### **RESOURCES** (Presenter: tailor resources to location of presentation)

- Get to know some adults with your child's disability (Ask yourself, "What are some of the "possible lives" my child could have?")
- Disability groups
- Support groups
- Web sites

## Slide 10: Skill #2: Know the Key Players

### Skill #2: Know the Key Players

- Who is the director or decision maker?
- Are staff people public, non-profit, or private employees?
- How can you find a person's name?



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Why is this important? In order to influence someone to make a change you think is necessary for your child, you need to know who to talk to. You need to know who actually has the authority to make decisions and changes. Examples: Case manager for an Individualized Education Program (IEP) or social service, state insurance commissioner, state and federal legislators, city council members, county board members, medical directors, patient representatives, agency directors, supervisors, school administrators, etc.

Is there a hierarchy? Is there someone in the system with a higher rank or more authority? If

one person can't or won't help you, who is the next person with higher responsibility who might be able to help you?

How can you can find out this person's name? (*Presenter: ask group to add ideas, too.*)

- Ask for a list of client, customer, or service-user contact information
- Look on the Internet
- Find resources at a library
- Check a phone book
- Ask staff at your local parent center for ideas and contacts

It's also helpful to know if the staff people are public, non-profit, or private employees so you can understand their role. To learn this, ask who funds the agency or service. Is it funded by the public through taxes? Is it a non-profit that is probably funded by grants and donations? Is it a private organization funded by fees, donations, or earned income?

## Skill #3: Know Your Rights and Responsibilities

### Learn about them by:

- Reading Web sites
- Asking how service is funded
- Asking to see laws and policies
- Asking questions
- Joining a group

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## Slide 11: Skill #3: Know Your Rights and Responsibilities

Why is this important? Knowing who is in charge is not enough. Parents need to know the “rules of the game” too; parents need to participate from a position of knowledge as much as possible. Each agency or service provider has guidelines on how they work. They have procedures, forms, policies, and sometimes laws and regulations. Ask where you can find these in writing if available.

### Read Web sites

See what you can learn by reading the agency’s or service’s Web site. Type its name in a “search” box on the Internet.

### Find the funding sources

There is a direct link between how an agency or service is funded and your rights and responsibilities. If agencies or services are funded by the public, they are required to follow certain laws, not just policies. Publicly funded systems are supported by taxes and include public schools, all levels of government including cities and counties, and all government agencies. Other agencies and services are non-profits that are supported by fees, grants, and donations; or private ones that are supported by fees, donations, or earned income. Non-profit and private agencies and services typically have policies, or ways of doing their business. Ask to see these policies in writing.

It’s okay to ask the agency or service how it is funded.

### Ask questions

Agencies and services often have case managers, consumer representatives, or patient advocates. Ask to talk to someone about the rights and responsibilities of people who use this agency or service.

### Join a group

Where can you learn more? Ask your parent center if there are others you could talk to who are also working with this particular agency or service. Ask if there is a class you could take or a book you could read to learn more.

If your native language is not English, ask to see materials in your language or ask if the agency or service will provide an interpreter. Sometimes this is required, especially of government agencies.

## Slide 12: Parents as Partners

### Parents as Partners

#### Parents and professionals can be partners and:

- Work together
- Share goals
- Have individual roles
- Share authority
- Have different skills
- Solve problems

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Often, parents don't feel like "partners." Often parents don't even feel like "players"! But remember the Alice Walker quote – you do have power; you just need to use it.

Understanding the different roles and backgrounds of each participant may help you and staff members work together more effectively. Here are some differences to consider:

- Staff persons have chosen their careers, while most parents did not know that they would have a child with a disability.
- You will be involved with your children for life, while most agency and service staff will be involved with your child for a much shorter time.

- Professionals have formal training and usually receive payment for their role in your child's life.
- Both you and staff have the goal of providing appropriate services for your child.

#### Parents, please remember:

- Parent knowledge and opinions are valuable. No one else knows what you know about your child.
- Only parents have an in-depth, long-term, daily relationship with the child.
- Parents can learn new skills to advocate and communicate clearly and assertively.
- Parents often have the power of giving or withholding consent for services.

#### Partners who work together:

- have the same overall purpose or goal; partners want a win-win situation,
- make an effort to communicate clearly,
- have respect for what each partner brings to the relationship,
- have individual roles or jobs and a clear understanding of each,
- have authority to make changes with the permission of the other partners,
- have opportunities for giving feedback to one another,
- bring different skills and information to the endeavor,
- are accountable for the results,
- use problem-solving strategies as early as possible. Don't focus on who was wrong, but on what went wrong and how can the partners can fix it.

These concepts can apply to parent and agency or service partnerships. The "business" of this partnership is providing appropriate services for your child. When the adults are "partners," your child will benefit.

#### RELATED ACTIVITY

"Introducing Your Child to the School Community Using a 'Student Snapshot' Format". See appendix for handout.

#### PRESENTER NOTES

Share this Casey Stengel quote: "It's easy to get good players. Getting 'em to play together – that's the hard part."

## Slide 13: Skill #4: Become Well Organized

### Skill #4: Become Well Organized



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- Keep records
- Put it in writing
- Keep a phone log
- Have a meeting notebook

Why is this important? Most agencies and services require documents, data, records, etc. So be well prepared by organizing what you have. You never know what you might need in the future.

#### Keep records

- Separate your records by service or agency. For example, school records may go into a special education record keeping folder, while health records may go in another folder or box.

- Keep written correspondences, including printed e-mails, from school, SSI, county services, medical professionals, or any other system.
- Keep a list of names and contact numbers for each system you deal with.
- When you go to a meeting, bring all the pertinent records from your file or folder. Keep them in order by date so you can easily find what you need.

#### Put it in writing

It is always best to get as many things in writing as possible. This includes copies of any letters or e-mails you send yourself. Also keep copies of letters and e-mails you receive from others. We have a saying in advocacy circles: "If it's not in writing, it doesn't exist." Someone may have told you something on the phone or in a hallway conversation, but it may mean nothing because it wasn't documented in writing. If that is the case, you might write a letter or e-mail saying something like, "Thank you for talking to me today. I think what you said was... and that you will... Unless I hear from you in writing by next week, I will assume you understood the conversation the same as I did."

#### Keep a phone log

Include the date, name of the person you talked with, a summary of what was said or decided, and brief notes of what was discussed. If there were any specific things that you or the other person agreed to do, highlight them in your log so you can check on progress later.

#### Keep a meeting notebook

Include the date, who was there, and brief notes of what was discussed and decided. Again, if there were specific things you or others were going to do, highlight that for follow-up.

## Slide 14: Skill #5 Use Clear and Effective Communication

### Skill #5: Use Clear and Effective Communication

- Keep your eyes on the “prize” – the right service for your child!
- Listen and ask questions



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Why is this important?

The only person you have the power to change is yourself. This is about “you” and not “them.” The way you talk to others has a direct relationship to how they interact with you and perhaps what services your child will receive. If you have a habit of showing strong emotions, ask yourself, “Will this get what my child needs today as well as tomorrow?”

The power we talked about earlier is not the same as aggression. If you behave with anger, others will likely only remember that you were angry,

not that you had good points or valid requests. Here are some tips that can really make a difference when you are advocating for your child.

#### Keep your eyes on the prize

The “prize” is effective service for your child with a disability. The focus should always be on the child and what the child needs, not what you need.

#### Listen and ask questions

Listen to others and ask any questions you have.

Listening gives you information you will need. Listen to see if the speaker is sharing opinions or facts. A fact will have data or records to back up what is said. Decisions should be based on facts.

Whether you agree or not, try to understand what others are saying.

**To make sure you understand what the other person is saying:** You might say: “I think I heard you say ... Is that correct?” Or, “Tell me more so I’m sure I understand your view.” Or, “Please explain that to me in another way so I’m sure to understand.”

#### RELATED ACTIVITY

Ask participants, “If someone says “your child is disruptive” what does that mean?” Ask for ideas. You can also add: Do you know when your child does this? How often? What specifically he does? Who does he disrupt? Knowing the answers to all these questions will determine what is actually done about the problem.

Ask who, what, where, and how questions, but be careful of why questions especially if it seems like you may be questioning someone’s motivation (why did you do that?). A why question like “why is my son taking that medication?” is certainly appropriate.

## Skill #5: Use Clear and Effective Communication

- Focus on needs of the child
- Problem solve together to find solutions



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## Slide 15: Skill #5 Use Clear and Effective Communication

Focus on NEEDS of the child, not on the solution you want. Keep the emphasis on what your child needs, not simply on a service you may want for your child. Use data or facts instead of opinion to support what you think your child needs. (Expect the professionals to use data too. If you or professionals do state an opinion, just be sure everyone knows it is an opinion and not a fact.)

**Problem solve together to find solutions** (bring the problem to the discussion table, not the solution).

- Describe the problem clearly.
- Encourage input from all members of the team.
- Brainstorm without evaluating the ideas: don't make judgments on how good the idea is. Just list options.
- Choose a solution by consensus (all agree).
- Develop a plan. Define who is responsible for an action and when will it be done.
- Put that plan in writing.
- Create a timeline and criteria to evaluate success.
- Follow up to make sure the plan is implemented.

## Skill # 5: Use Clear and Effective Communication

- Speak clearly
- Avoid making people feel defensive
- Turn negatives into positives
- Summarize



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## Slide 16: Skill #5 Use Clear and Effective Communication

### Speak clearly

Be as clear and direct as possible so that others will understand what you have to say.

Give specific examples if you can. Instead of saying “she always has a stomachache,” you might say “she always has a stomachache when she gets home from school.”

Describe why something will help. Describe how something will help.

If you say, “my child needs paraprofessional support,” what could you add to explain why or how that will help?

- Avoid making people feel defensive.
- Don't criticize: With each criticism, defensiveness increases and listening decreases.
- Give positive feedback and praise as often as possible.
- When people don't listen, they are unlikely to do what I think they should do!

### Turn negatives into positives

This technique allows you to take a negative comment made about your child and turn it into a positive. For example, “He's always fighting” could mean “It looks like my child needs to learn social skills.”

### RELATED ACTIVITY

What is something negative a person has said about your child? How could you rephrase that into a request for service?

**Summarize** what you and others have said. Ask if you've misinterpreted or misunderstood anything, and ask to be corrected if you have. Ask if someone is writing down what was discussed and decided. Ask for a copy.

## Tips for Good Communication at a Meeting

- Focus on your goal
- Show respect and expect it from others
- Manage your emotions
- Ask questions
- Rephrase for clarification
- Say thanks

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## Slide 17: Tips for Good Communication at a Meeting

The previous slides have covered most of these tips.

### RELATED ACTIVITY

Ask volunteers to take part in role plays of two, five-minute meetings. You may ask for volunteers at this time or before the workshop has begun. During the first meeting, tell volunteers that they should NOT follow any of the tips. During the role play of the second meeting, ask the volunteers to try to follow all of the communication tips. The topic for both meetings is that the parent thinks the city should

have accessible playground equipment. The “players” will be the parent, a city council person, and the park superintendent. Tell participants, “Let’s see how each meeting ends.” Ask: “What did you learn? What could be done differently so this child has accessible playground equipment?”

## Tips for Written Communication

### Letters should:

- Be sent to person who can make a change
- Be dated and signed
- Focus on one or two issues
- Be no longer than one page
- Set a deadline if a reply is requested
- Give your contact information

**Remember to keep a copy for yourself!**

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## Slide 18: Tips for Written Communication

Put it in writing:

As we stated before, there is a saying in advocacy circles: “If it’s not in writing, it doesn’t exist.”

Letters may be sent for such reasons as:

- Making a request
- Asking for clarification
- Clarifying what you yourself want to say
- Asking for a decision
- Saying thank you
- Documenting a verbal discussion

Use the checklist on the slide when you write a letter or e-mail to help you remember these important points.

## When You Disagree

- Disagree without being disagreeable
- Apologize if needed
- Separate the person from the problem
- Realize NO ONE has all the answers
- Make sure your facts are correct
- Choose your battles

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## Slide 19: When You Disagree

When parents and agencies or service providers disagree, there are things you can do or say that will help the disagreement be solved more quickly and amicably, no matter which process is used:

- You can disagree without being disagreeable. Express that you want to continue to work together for the benefit of your child, and that you do not want this agreement to interfere with that.
- Sometimes you might be partly responsible for this disagreement. Accept responsibility for your part. Apologize if it's appropriate.

- You are an advocate for your child only. The professionals you may disagree with work for an agency or service provider. They must not only answer to you but to their agency. Oftentimes it is not the person you are disagreeing with at all, but the agency. So separate the person from the problem.
- Each person involved in this disagreement brings different information, values, priorities, etc., to the table. No one has all the answers. Try to work together using everyone's input to solve the problem. Help people make sure their facts are accurate so decisions are accurate.
- Not everything is worth disagreeing about. Choose your battles or you and those you deal with will just become weary and wary. Your child will not benefit when the adults are worn out by disagreements. Stick to those disagreements that really affect the quality of service for your child.

## Skill #6: Know How to Resolve Disagreements

### Informal Processes:

- Talk to people first



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## Slide 20: Skill #6: Know How to Resolve Disagreements

Why is this important? As a parent, you may agree or disagree with the decisions made by an agency or service provider. If you look back at Skill #3, you'll be reminded that knowing who is in charge is not enough. Parents need to know the "rules of the game," including how disagreements are settled with a specific agency or service provider. Each agency or service provider has formal or informal guidelines on how it works; each one has procedures, forms, policies, and sometimes laws and regulations. Ask if the agency has a dispute resolution procedure. Ask where you can find it in writing.

**There are many ways to resolve disagreements.** It's usually best to use informal means. Start your efforts at the level closest to the problem. Talk to people, such as the case manager or service provider, about your differences and be clear about why you do not agree. This often is the easiest way to solve a problem. Often, a compromise or "trial solution" may work. You may say, "I don't really know if this would work, but could we try \_\_\_\_\_ until \_\_\_\_\_ and see how it goes?"

## Skill #6: Know How to Resolve Disagreements

### Formal Processes:

- Mediation
- Complaints
- Appeals



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## Slide 21: Skill #6: Know How to Resolve Disagreements

Sometimes more formal means are necessary to clear up disagreements. Among the options may be:

### Mediation

Agencies and service providers sometimes provide mediation where the parties who disagree meet with a neutral mediator. The parties, not the mediator, make the final decisions. The mediator guides the discussion so that all sides and options can be heard.

### Filing complaints

Some agencies and service providers have a formal means of filing a grievance or complaint.

### Filing appeals

Some agencies and service providers have a written process for filing an appeal of a decision made by the agency or provider. Government agencies must have an appeals process. In addition, insurance companies also have an appeal process if a claim or procedure is denied.

What if it doesn't work? You may ask, "why bother to appeal (or complain) if it didn't work before?" You've probably heard the saying "the squeaky wheel gets the grease." This simply means that those who speak up and are persistent often get the services their child or family needs. Even if we hear "no" today, we may hear "yes" tomorrow.

### How can you find out more?

**Read Web sites:** See what you can find on the agency's or service's Web site. Type its name in a "search" box on the Internet.

**Check the funding:** There is a direct link between how an agency or service is funded and your rights and responsibilities including resolving differences. Those funded by the public through taxes, such as public schools, all levels of government including cities and counties, and all government agencies, are required to follow certain laws. Other agencies or services are non-profit or private, and these typically have policies on how to resolve differences. Ask to see these policies in writing.

**Ask:** Agencies and services often have case managers, consumer representatives, or patient advocates. Ask to talk to someone about the rights and responsibilities of users of the agency or service.

**Join a group:** Where can you find out more? Ask your parent center if there are others you could talk to who are also working with this particular agency or service. Ask if there is a class you could take or a book you could read to learn more.

## Skills Checklist

- ✓ What have you learned?
- ✓ Is there a skill you hope to improve?
- ✓ Do you need more resources?
- ✓ Do you need more support?

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## Slide 22: Skills Checklist

- Understand your child's disability
- Know the key players
- Know your rights and responsibilities
- Become well organized
- Use clear and effective communication
- Know how to resolve disagreements

### RELATED ACTIVITY

Lead a discussion based on slide.

## Summary

**"I am only one, but still I am one. I cannot do everything, but still I can do something. I will not refuse to do the something that I can do."**

—Helen Keller

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## Slide 23: Summary

The only person you can change is you. No matter how much you wish the other person would learn some of these skills, you can't force it to happen. But you DO have the power to change and grow yourself.

As the saying goes, "Every journey begins with one step." As you work on your skills, you will find yourself becoming more confident and effective.

And through this process, you can make a great difference in the life of your child with a disability.

## Contact Information

National Family Advocacy Supports and Training (FAST) Project:

[fastfamilysupport.org](http://fastfamilysupport.org)

888.248.0822

(toll-free nationwide)

The FAST Project is funded by the Administration on Developmental Disabilities (ADD) as a Project of National Significance.

FAST is a project of:

**PACER CENTER**  
CHAMPIONS FOR CHILDREN WITH DISABILITIES™

PACER.org | 952.838.9000 | 888.248.0822

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## Slide 24: Contact Information

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Des Jardins, Charlotte. (1993). How to Get Services by Being Assertive. Family Resource Center on Disabilities. Chicago, IL (312) 939-3513.

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## **GENERAL DISABILITY**

“Partners in Living, Time, Education, and Employment” (online courses offered by Partners-In-Policymaking) at <http://www.partnersinpolicymaking.com/online.html>



**Skills for Effective Parent Advocacy**

# Appendix

*Sample Workshop Flyer*

*FAST Online Handout*

*Evaluation*

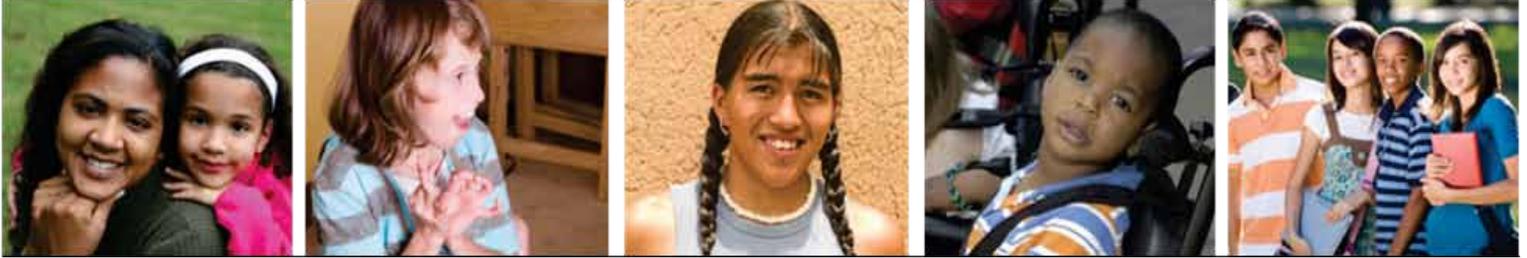
*Introducing Your Child to the School Community Using a  
“Student Snapshot” Format*

*Communicating about Services for your Child*

*Attending Meetings to Plan Your Child’s  
Individualized Education Program (IEP)*

*How Can My Child Be Involved in the IEP Process?*





# Skills for Effective Parent Advocacy

A curriculum created by the National Family Advocacy Support and Training (FAST)  
Project, a project of PACER Center: [fastfamilysupport.org](http://fastfamilysupport.org)

*Workshop Date*

*Location*

*Parent Center Name*

*Presenter*

# FAST online

## Family Advocacy Support and Training (FAST) Project *a project of PACER Center*

Visit FAST online today at [www.fastfamilysupport.org](http://www.fastfamilysupport.org).

### Web site features include:

- ✓ State and National Resources for families
- ✓ Skills for Effective Parent Advocacy Training and Handouts (English and Spanish)
- ✓ Getting and Keeping the First Job Training and Handouts (English and Spanish)
- ✓ The Journey to Adulthood: What Parents Need to Know Training and Handouts (English and Spanish)
- ✓ Working for Change: The Power of the Personal Story Training and Handouts (English and Spanish)
- ✓ A National Survey on Family Support Needs
- ✓ Connection to FAST's facebook page and more



*The FAST Project is funded by the Administration on Developmental Disabilities (ADD) as a Project of National Significance.*

# Skills for Effective Parent Advocacy Evaluation

FAST Workshop

**We'd appreciate your feedback on this workshop.**

**1. Are you a: (Please check all that apply)**

- Parent       Surrogate / Foster parent       Grandparent       Other relative/guardian       Regular educator  
 Special educator       Professional       Student       Administrator       Other (please specify) \_\_\_\_\_

**2. What is your child/young adult's age?** \_\_\_\_\_

**3. Does your child/young adult have a disability?**     Yes (please answer #4)       No (skip to #5)

**4. What is your child/young adult's primary disability? (Check one)**

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> ADD-ADHD                              | <input type="checkbox"/> Mental Illness                       | <input type="checkbox"/> Specific Learning Disability          |
| <input type="checkbox"/> Autism                                | <input type="checkbox"/> Developmental Cognitive Disabilities | <input type="checkbox"/> Speech/Language Impairment            |
| <input type="checkbox"/> Deaf-Blindness                        | <input type="checkbox"/> Multiple Disabilities                | <input type="checkbox"/> Traumatic Brain Injury                |
| <input type="checkbox"/> Deaf-Hearing Impairment               | <input type="checkbox"/> Orthopedic Impairment-physical       | <input type="checkbox"/> Visual Impairment including Blindness |
| <input type="checkbox"/> Developmental Delay (Early Childhood) | <input type="checkbox"/> Other Health Impairment              | <input type="checkbox"/> Suspected Disability _____            |
| <input type="checkbox"/> Emotional Disturbance                 |   |  |

**5. On the whole, how would you rate this workshop?**

- Excellent       Very good       Good       Fair       Poor

**6. Have you learned anything new at this workshop?**     Yes       No

I found these topics most worthwhile: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**7. Has this workshop helped you learn how to more effectively advocate for your child?**       Yes       No

**8. Were the materials received at this workshop of high quality?**     Yes       No

**9. What suggestions do you have for improving this workshop?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**10. Other comments** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## Introducing Your Child to the School Community Using a “Student Snapshot” Format

As the expert on your child, you, the parent, have valuable information to share with the people who will interact with your child during the school day. Some school staff members will attend Individualized Education Program (IEP) meetings, but many will not have the opportunity to be a part of in-depth discussions about your child. IEP case managers are often reluctant to share student-specific information with other school personnel because of concerns about confidentiality.

If the only information someone has about your child is a special education label, that person may make assumptions about your child that are not accurate. If the person has no information at all, he or she may misunderstand your child's performance and behavior at school. For example, the cafeteria worker may try to engage your child in friendly conversation as he moves through the lunch line. If she is not aware of his hearing impairment, she may view his lack of response as rude and disrespectful behavior and discontinue attempts to talk or interact with your child.

**Because** families have differing viewpoints on how much information to share and with whom, parents can take the lead when it comes to providing personal information about their child at school. **Because** time is often in short supply for both you and school personnel, it is important to find a way to deliver information quickly and concisely. Lengthy reports, multiple-page e-mails and prolonged telephone conversations are not efficient and rarely effective. One-page written materials are much more likely to be read and remembered.

Use the template provided on the reverse side of this handout to prepare a one-page “Student Snapshot” of your child. The process of completing the form will help you:

- Determine what is most important to you and your child.
- Develop the ability to express those concerns and expectations in clear and concise ways. Examples of the kind of statements to include are given on the template to help get you started.

### Tips and Suggestions

- **Keep it simple:** Use only one side of one page. Use bulleted lists rather than paragraphs. Avoid medical

terminology and jargon—use everyday or school-related language whenever possible.

- **Prioritize:** Include no more than five or six points in each of the five areas on the template. Don't duplicate the IEP. The “Snapshot” includes only a few of the most essential considerations of which all staff should be aware.
- **Keep it personal:** Be sure to include a current photo of your child. Information should be specific to your child, not about the disability in general.
- **Involve your child:** Be sure to include your child in decisions about what information to share and with whom.
- **Decide who needs a copy of the “Snapshot”:** Consider the following: librarian, secretary, nurse, custodian, cafeteria supervisor, bus driver, after-school child care or activity director, principal, counselor, art and music teacher, playground supervisor, paraprofessional, classroom teacher. Ask to have a copy included in the teacher's or paraprofessional's substitute folder.
- **Distribute the “Student Snapshot”:** Provide a copy when you introduce your child and yourself to school staff at back-to-school activities. Distribute to the IEP team at the annual IEP meeting. Provide a copy when there is a change in personnel working with your child.

## Introducing Joe Smith

### Joe Smith at a Glance

Current Interests: Spongebob Squarepants®, playing the drums, Twins' baseball

Likes: Computers, electronics, art and media materials

Dislikes: Noisy environments, touching or tasting unfamiliar foods

Motivated by: Coaching style: setting and reaching goals, "high fives," humor (good-natured teasing); social interaction; grades and awards

Turned off or discouraged by: Stern or angry responses, being singled out publicly



### Joe's Strengths to Build Upon

- Good auditory memory; learns best by listening
- Musical: rhythm, rhyme and melodies reinforce learning
- Cooperative: works well in teams or small groups
- Understands limits: able to follow rules
- Uses laptop computer independently
- Supportive and involved family

### Joe's Challenges and Ways to Address Them

- No hearing in left ear: Speakers need to sit, stand, and walk on his right side.
- Younger developmental age: Close adult supervision needed for vulnerability and safety, especially during unstructured times like recess, lunch, and hall passing times
- Poor fine motor skills: Needs extra time, adapted materials, and some personal assistance for writing or drawing and self-help activities.
- Poor large muscle coordination and balance: Needs extra time and more space going up and down stairs and moving through halls

### Our Long-range School Goals for Joe:

- To participate as much as possible in school with the people with whom he will live in the community as an adult (regular education peers)
- To reach his potential in basic skill areas: reading, math, written language
- To develop age-appropriate behavior and social skills
- To learn what he has to offer others and to feel a responsibility to make a contribution
- To increase his attention span and tolerance for mentally and physically challenging activities

### Our Focus for Joe this School Year:

- To make measurable progress in reading, especially decoding
- To learn appropriate conversational skills with peers
- To make a friend with whom to connect outside of school

**Introducing** \_\_\_\_\_

\_\_\_\_\_ **at a Glance**

**Current Interests:**

**Likes:**

**Dislikes:**

**Motivated by:**

**Turned off or discouraged by:**

\_\_\_\_\_ **'s Strengths to Build Upon**

- 
- 
- 

\_\_\_\_\_ **'s Challenges and Ways to Address Them**

- 
- 
- 
- 

**Our Long-range School Goals for** \_\_\_\_\_ **:**

- 
- 
- 

**Our Focus for this School Year:**

- 
- 
-

## Communicating about Services for your Child

Parents can bring someone else with them to most meetings. All participants are working together to benefit the child.

Effective communication is two-way, generating the understanding and support the professionals and the parents all need to make effective decisions about the child's educational program. To foster meaningful communication, parents can:

- Make sure the focus stays on the child.
- Be prepared. Know in advance the important points to discuss and questions to ask. Write them down and check them off as they are addressed.
- Listen. Listening will help you gather information about your child and help you understand other viewpoints.
- State your issues clearly. Communicate in an honest and direct manner.
- Ask questions. Asking questions can be an effective way of clarifying a point and keeping the line of communication open.

- Comments and questions should be directed to the person who can best address or answer them.
- Restate your concerns if you are not heard the first time.
- Be confident. A parent never has to feel guilty or embarrassed asking questions or assertively pursuing the appropriate services for the child. It is your role and your right.
- Work together. Remember that neither you nor the professionals have all the answers. Work together as a team to find solutions. Everyone at the meeting has the same goal — to provide an appropriate educational program for the child.

The key to effective communication is preparation and willingness to be actively involved. This includes involving the child in the meeting, if appropriate. It is a great example for a child to see parents and professionals working together for the child's benefit.

## Attending Meetings to Plan Your Child's Individualized Education Program (IEP)

### Before the IEP planning meeting:

- Consider the vision you have for your child for the future as well as for the present year.
- List your child's strengths, needs, and interests and your major concerns about his or her education.
- Consider how your child's disability affects his or her education.
- Think about your child's educational progress. What has been working and what has not?
- Request a written copy of your child's evaluation results or a meeting with school staff to discuss the evaluation before the IEP meeting. This gives you an opportunity to understand the evaluation before the IEP planning for your child.
- Consider the evaluation results. Do they fit with what you know about your child? Is the evaluation complete and accurate? If you disagree with the school's evaluation, you may request, in writing, an independent educational evaluation (IEE) at no cost to you. The school must provide the evaluation or show through a due process hearing that its evaluation is appropriate. The results of an IEE must be considered by the team in planning.
- Consider a variety of ways to involve your child in planning his or her IEP, starting at a young age. Self-advocacy skills are important to develop.
- If needed, plan to bring someone with you to the meeting, such as a spouse, relative, friend, or representative from a local disability organization.

### At the IEP planning meeting:

This meeting is very important. You, the school staff, and any other parties attending the meeting will review and discuss information about your child to plan the IEP. It provides an excellent opportunity to ask questions and share important insights about your child, whom you know better than anyone else does. The school needs to know what your child is like at home and in the community, as well as what your child's interests and activities are.

- Make sure others at the meeting never forget that the

meeting is about a real child.

- Share your visions for your child, both short-term and long-term.
- Discuss your child's strengths and needs and your concerns about your child's education.
- Remember that diagnostic tests and assessments do not present the total picture.
- When you believe that the teacher and school personnel are doing a good job, tell them so. Praise, when deserved, is a great thing.
- Be a good listener. Ask questions.
- Make sure you understand. If you don't understand something, ask to have it explained in a way that you can understand.
- Expect that what you know about your child will be used in making decisions.
- Use school data, your child's progress reports, and other information you know about your child to make decisions.
- Take the proposed IEP document home to review or ask that a copy be sent to you. You probably will not want to agree to a proposed IEP at the end of the meeting. You have 14 calendar days from the time you receive the written IEP to agree or disagree with the program in writing and return it to the school.

### After the IEP planning meeting:

- Your child's IEP must be reviewed at least once a year to determine whether the annual goals have been achieved and to revise the IEP if necessary.
- You must be informed regularly about your child's progress, at least as often as parents who have children without disabilities are informed about the progress their children are making. You will be informed about whether your child is making progress toward meeting the IEP goals, and whether the progress is enough to reach the goals. If your child is not making adequate progress, an IEP meeting should be held to review the IEP and make needed changes.
- You may request an IEP meeting at any time.

## How Can My Child Be Involved in the IEP Process?

The Individuals with Disabilities Education Act (IDEA 2004) states that a child should attend his or her individualized education program (IEP) conference, if appropriate. Each family must decide if the child should attend, based on individual circumstances. Families who include their child in the IEP meetings report that the child's presence puts the focus on the child.

The child must be invited any time transition needs or services are discussed. It is essential that adolescents participate in IEP development because this is a major part of their lives, and they need to take charge of it as much as possible.

Children need as much practice in self-advocacy as possible before they reach the age of majority (18), when parental rights transfer to the special education student, unless guardianship or conservatorship has been established. Self-advocacy skills prepare students for the world and their future beyond high school.

The IEP conference provides an excellent opportunity for self-advocacy and learning important life skills by helping the student:

- practice goal-setting and teamwork
- understand the impact of his or her disability
- learn how to ask for and accept help from others
- understand his or her own strengths and needs
- express his or her own needs and concerns
- participate in a process of resolving differences

Some parents have concerns about involving their children in IEP meetings. Here are some common questions you can ask to help decide how best to involve your child.

### **I think my child is too young to participate.**

Ask your child if she has anything she'd like you to share at the meeting. Afterward, sit down with your child to explain the goals you and the school discussed for the next year. Talk with your child about these goals before you sign the IEP.

### **I've never taken my child before.**

Discuss the meeting process with your child. Would he like to attend or would he like to attend part of the meeting (at the beginning to introduce himself and his interests or at the end to review what the team has proposed)? Would your child be willing to share ideas and opinions at the meeting or on paper? How would your child react if something negative were said about him?

### **My child chooses not to attend.**

Discuss what your child would like you to say to the team on her behalf. Consider taking notes to read at the meeting, or read what your child has written. Ask your child:

- What do you want to learn this year?
- What are your special concerns for this school year?
- How do you learn the best?
- What do you need to be successful?
- What would make learning easier for you?

### **The meetings are too stressful, too negative for my child.**

Talk with your child about what he wants to say. Help him phrase and practice statements before the meeting, or help him write notes or an outline of what to say. Consider inviting your child to only part of the meeting. Ask your child to share his strengths, interests, and accomplishments at the beginning of the meeting. You can also let him invite someone who will help him feel more comfortable. If a meeting becomes too difficult for your child, the meeting can be stopped or the child could be allowed to leave.

### **My child attended, and it didn't work.**

Rethink the circumstances and what happened. Can any of the above suggestions be tried? Don't let one incident determine that the child will never participate again.

**FAST is a project of:**

