

- ⇒ This booklet was written and printed by Family to Family (F2F), a project funded by the Family Social Services Administration (FSSA).
- ⇒ F2F offers information, resources, and connections for families nurturing children with disabilities. F2F staff, spread across Indiana, are experienced parents of children with disabilities. F2F coordinates a network of parent volunteers (Points of Contact) who support parents across the state.
- ⇒ F2F assists parents who wish to connect with their local First Steps councils. We believe parent input in the First Steps system is vital. We also assist parents who are interested in becoming co-trainers. These parents can then help train professionals by speaking during trainings, panels, and conferences.
- ⇒ F2F helps families to connect with one another online. The F2F listserv is for all families of children with disabilities. Group members exchange information and resources with one another. Common topics include transition, Individualized Family Service Plans (IFSPs) or Individualized Education Programs (IEPs), and questions about types of therapies/diets/surgeries. To join, send an email to INF2FParents-subscribe@yahoogroups.com.



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IN YOUR CHILD'S BEST INTEREST...



Tips for Working as a Team with
Professionals to Advocate for your Child

www.INF2F.org

DEAR PARENTS,

If you are a parent of a child in the First Steps system, you have probably heard the word “transition”, which means “change”. No doubt you and your family have experienced your own transitions over the years. One particularly noteworthy transition occurs when your child turns three and exits First Steps. You’ll hear a lot about this transition because, for many families, it marks a significant change for the child as well as for the family as a whole. And let’s face it, change can be difficult. Particularly when the change involves moving from participating in early intervention (where a service coordinator assists with services, support, and advocacy) to navigating service systems on your own.

Now more than ever, you, the parent, must take on the role of advocate for your child. This means being actively and positively involved with the professionals in your child’s life. As you may already have discovered, there are many situations that may require you to be an advocate for your child: at school meetings, in doctor’s offices, in hospital rooms, on the phone with insurance representatives, in conversations with people from your church, the daycare, etc. Being your child’s advocate can be tricky; you need to be firm and confident enough to influence professionals and help them to see your perspective, but you don’t want to be perceived as negative or pushy. The advocacy tips in this booklet have been used successfully by other parents of children with disabilities and were compiled to help you become a more effective, positive advocate for your child. Good luck!

—FAMILY TO FAMILY STAFF

WHEN TEAM MEMBERS DISAGREE:

This booklet has focused on ways to advocate for your child in a positive and relationship-building manner. In the majority of cases, this approach to advocacy will lead you to the outcomes you need in order for your child to succeed. However, *you can only control your own behavior*. Periodically you may encounter an individual who seems unwilling to engage in constructive, respectful interactions. If this is the case, consider the following options:

- ⇒ **Ask for advice from other parents of children with disabilities** who have successfully navigated a similar situation.
- ⇒ **Talk openly with the individual** about past negative interactions and express a desire to work on the relationship.
- ⇒ **Find someone new to partner with, if that is an option.** Look for professionals who are upbeat, creative and flexible!
- ⇒ **If you have already tried talking to this individual, consider talking to someone higher in the hierarchy** like the clinic director, school principal, hospital administrator, director of special education.
- ⇒ **Most organizations have a set of procedures in place to address concerns.** Review your procedural safeguards, parent rights, or patient rights documents to find out what is needed to put your concerns on record or file a complaint. This should be your last resort; try the options above first!

TAKE HOME MESSAGE:

Usually being positive, assertive, and willing to compromise will help you to achieve your goals. If it doesn’t, consider the pros and cons of your alternatives and decide what is best for your child.

GETTING TO KNOW THE PROFESSIONALS WHO WORK WITH YOUR CHILD:

Sometimes parents have a reputation for only being seen when something is going wrong. It is important to interact with professionals in positive ways on a regular basis. Here are some ways to do this:

- ⇒ **Engage in routine communication.** Consider “checking in” with your child’s professionals every few weeks, even if there aren’t any problems to discuss. You could do this via email, a notebook, a phone call, or a brief visit, depending on the situation. By asking how things are going on a regular basis, you keep the lines of communication open and you let the professionals know that you want to be involved in your child’s care. Share information about positive things going on in your child’s life as well as discussing the problems.
- ⇒ **Express appreciation.** Write a quick note or send a brief email when your child’s case manager/teacher/doctor/therapist does something particularly helpful or kind. Bake cookies for no reason and drop them off in the teachers’ lounge or the nurses station at the hospital. Leave a Starbucks gift card for that therapist who always talks lovingly of her morning coffee.
- ⇒ **Offer to volunteer.** Join the First Steps council, help out in your child’s classroom once a month, or join the PTA. If you work full-time, consider ways to volunteer that can be done in the evenings or weekends (e.g., stuffing envelopes, baking muffins for class snack).



PREPARATION:

- ⇒ **Educate yourself.** Learn everything you can about your child’s diagnosis, insurance coverage, education law, etc. This will help you to feel like an equal when you talk with professionals.
- ⇒ **Find other parents who have “been there, done that”** and get briefed on how things work with your local pediatrician, school system, parks and recreation department, hospital, etc. The F2F listserv is an excellent way to connect with other parents in your area (email: inf2fparents-subscribe@yahoogroups.com or call 1-800-396-7188). Also About Special Kids (formerly IPIN) (www.aboutspecialkids.org or 1-800-964-4746) offers a local support group directory.
- ⇒ **Bring documentation** (e.g., reports from private therapists, notes with dates, specific events) to support what you say. You don’t want to rely on memory when you may be nervous.
 - ◆ *you are concerned about your son’s tendency to “space out” but your doctor isn’t taking it seriously. Keep a chart of every time it happens (date, time, what he was doing at the time, etc.) and bring it with you to your next appointment.*
- ⇒ **Write out proposed goals/questions/concerns and share them with professionals before the appointment.** This allows for the possibility of some advance discussion and problem-solving to take place. Try to include some long-term goals; ideally you want your child’s team of professionals to be thinking about and planning for what s/he is going to be doing five or ten years down the road.

PREPARATION CONTINUED:

- ⇒ **If evaluations were performed, ask for the results before the meeting** so that you can read and digest them privately.
- ⇒ **If your appointment is school-related, read about special education law;** the more knowledge you have, the more confident you will feel. For a copy of Indiana's special education law, go to: www.doe.state.in.us/exceptional/speced/pub_article7_2002.html or call 1-800-833-2198.
- ⇒ **Prioritize your issues.** Make a list of concerns from most important to least important. Know which issues you can't compromise on and which ones you can. Your flexibility on minor points will be appreciated!
- ⇒ **Don't rely on professionals to do everything.** If you think your child needs something (e.g., a piece of equipment, a new therapy approach), do some research beforehand. Come up with some proposed solutions, and be ready to suggest them. Be creative!
 - ◆ *Sarah thinks a walker would benefit her son. Her child's therapist isn't sure. Instead of getting frustrated, Sarah does some research (e.g., explores companies online, talks with other parents, makes a list of the features that she thinks are important) and shares her findings with her child's therapist.*
 - ◆ *John knows that his daughter will have trouble using the regular school markers. Instead of demanding that the school find a solution (John has other issues that he wants to focus on), John brings in a set of markers from home and makes an adaptive marker holder for the school to use.*

- ⇒ **Control your emotions.** It isn't possible to turn off your emotions completely. The trick is to keep them to yourself. Others will respond to this and treat you accordingly. Professionals will be more willing to talk openly and problem-solve if they aren't worried about displays of negative emotion. After this encounter is over you can deal with those emotions (e.g., share what happened with a friend/spouse, write in a journal).
- ⇒ **Line up a friend or support person to be available after your appointment.** Take a little time after the appointment to debrief with someone before diving back into your regular routine.
- ⇒ **Take care of yourself.** Advocating for your child can be emotionally draining, even when it goes flawlessly! Give yourself a treat after attending a difficult meeting or therapy session. Stop for a cup of coffee or an ice cream. Buy your favorite magazine and read it after the kids go to bed. If you don't take care of yourself, you won't be able to do your best for your child.



TAKE HOME MESSAGE:

Reining in strong emotions will help you to have a good relationship with the professionals in your child's life. Professionals who feel appreciated and respected may be more willing to go out of their way to respond to your requests.

HOW TO ACKNOWLEDGE YOUR FEELINGS AND MOVE ON:

- ⇒ **Remember to do your homework** before the appointment so that you aren't blindsided emotionally by issues or information you didn't anticipate.
- ⇒ **If you are blindsided, explain what it is that you are having trouble processing and then take a break to regroup.** If you don't think you can continue, ask to reschedule the meeting. This may feel awkward, but it will be better than trying to continue when your emotions are not under control.
- ⇒ **Try to let go of any past negative interactions** and start new. You don't have to forget past issues, but if you have had previous difficulties, try to put them aside and start fresh. Focus on the needs of your child rather than the personalities of the individuals in the meeting.
- ⇒ **Consider bringing your child to the meeting.** Your child's presence will serve to remind everyone about what is important and s/he may have some important input. Some parents don't feel comfortable having their child present for the entire meeting. Alternatives include having the child attend a portion of the meeting or provide written input. Some parents bring a picture of the child to share.
- ⇒ **Don't personalize what professionals say.** Your emotions will get in the way of the process. Try to take statements at face value and move on.



- ⇒ **Practice bringing up issues with your spouse or a friend a few days or weeks before talking to the professionals.** If you practice, you will sound more confident. If you have a difficult issue to raise, it helps to have thought about the actual wording you will use.

TAKE HOME MESSAGE:

When you are prepared, it sends a message to professionals that you are an equal member of the team, and it boosts your confidence!

AT THE MEETING/APPOINTMENT:

- ⇒ **Avoid self-fulfilling prophecies.** If you go into a meeting expecting it to be negative, it probably will be! Expectations influence how you communicate. Assuming that an appointment will go smoothly helps you to communicate in a positive way, which makes it more likely that the session really will go smoothly!
- ⇒ **Bring your spouse or a friend** with you so that you aren't alone. Try to position yourselves so that it doesn't become a "parents on one side and professionals on the other side" situation. If you are attending a school meeting and want an experienced parent to go with you, consider contacting IN*SOURCE (www.insource.org or 1-800-332-4433). You may want to let the school know ahead of time that you will be bringing someone with you and tell them why so that they will be expecting another participant.
- ⇒ **Arrive early and greet professionals.** Greet people as they arrive and be friendly. Be sure you know everyone; if you don't, suggest introductions. Some parents like to bring food. Food can be a good icebreaker as well as an expression of appreciation.

AT THE MEETING CONTINUED:

- ⇒ **Speak confidently.** Even if you don't feel sure of yourself, force your voice to be calm and loud enough to be heard. If you act as though you are an equal player, people are more likely to treat you that way.
- ⇒ **Listen.** Sometimes we are so busy formulating our response that we forget to listen to what the other person is saying! One way to make yourself be a good listener is to repeat back what the person said ("So you think.....is that right?").
- ⇒ **First describe what is working** and then describe what you would like to see improved.
"I have been so pleased with my daughter's handwriting this year; it has improved so much! I'm concerned about her math skills though, I think she may need more one-on-one help in that area."
- ⇒ **"Sandwich" complaints between two positive statements.**
"I'd love to see my son play more with the other kids in his daycare. Right now I see him mainly playing by himself. How do you think we could help him begin to make friends?"
- ⇒ **Be specific.** Generalized criticism tends to be disregarded because most people recognize that there are some good things about almost any person or organization.
"This school never offers least restrictive environment (LRE) to anyone" (general) versus "I don't think my son is receiving services in the LRE this year because..." (specific)

- ⇒ **Don't criticize without suggesting a solution.**
"I am concerned because you have been late for my daughter's therapy sessions for three weeks in a row. Would you like to try scheduling the session for a later time to allow you more time to get here?"
- ⇒ **Avoid sarcasm.** It can be misinterpreted as disrespectful in a tense atmosphere.
- ⇒ **Take notes** at the appointment to help you remember what was said. If you bring a support person with you, this person can help you with this (it can be hard to listen, respond and take effective notes all at the same time!)
- ⇒ **Always thank professionals** for their efforts. Yes, it's their job, but everyone likes to be appreciated! Try writing a thank you note expressing appreciation and summarizing the important issues. Don't be surprised if you make someone's day!
"When my son's insurance company agreed to purchase a very expensive electric wheelchair, I wrote a thank you note to the company and included a picture of my son in his new chair. A week later the president of the insurance company called me and said how deeply touched he was to receive the letter."



TAKE HOME MESSAGE:

Don't say anything in a meeting that you would not want quoted on the front page of the newspaper with your photo beside it!