



**Building Partnerships
With Your
Child's Doctor
or
Health Care Provider**



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As a parent, you know your child better than anyone. You know how to make him laugh and how to soothe him, you know what her/his best qualities are and what she needs.

So when your child receives early intervention services or if your child has been just diagnosed, you play a key role in helping your child's doctor know and understand your child's strengths and needs, and what services would be helpful.

You can keep your child's doctor informed about the early intervention program and services your child receives, but you probably also want him or her to be involved. An "Early Intervention Partnership" and a "Family Professional Partnership" between doctors and parents often does not happen automatically. In fact, many times the most successful partnerships are because the parents—you made it happen!

There are many steps you can take to create the type of partnership and relationship that you want with your child's doctor or health care provider. This booklet gives suggestions and ideas for getting started with a new doctor and also for improving a partnership that you already have.



Choosing a Doctor or Health Provider

Here are some general qualities to look for:

Clinical skills and knowledge-Does he or she have the training and specialty interests important to your child's needs?

A doctor with a special interest in child development, special needs, or a specific diagnosis might be just what you are looking for.

Experience-Has the doctor or health provider cared for other children who have a similar diagnosis as your child or for children with developmental delays or disabilities in general?

This kind of experience will help your doctor or health provider to be more aware of resources and possible services your child and family could benefit from.

Mutual respect and a sense of connection-Is he or she approachable? Does he or she make you feel comfortable? Do you like the interactions with your child? Are you comfortable in your conversations with them?

Do you trust this person with the health of your child?

A doctor or health provider may be better in one area than another. Choosing a doctor may mean choosing a balance between technical skills, interpersonal skills, and experience. You decide what you and your child need right now. You may find that what you need changes over time.

Creating a Relationship with your Doctor or Health Provider

Be a partner-Decide what type of partnership you want with your child's doctor or health provider. How do you want him or her to be involved in coordinating care and services for your child? What role do you want in making medical and health decisions?

Whatever type of partnership you have, you should feel comfortable asking questions, sharing your insights, and feel like you and the doctor or health provider are part of a team.

In turn, you should be open to the doctor's or health providers questions, insights, and accept him or her as part of your child's team.



Creating a Relationship with your Doctor or Health Provider

Be a role model- Show by example how you want to be treated and how you want your child to be treated. If you want to be listened to, then be a good listener, too. If you want your doctor or health provider to be delighted with your child, then show your delight in your child.

Be understanding- Doctors and health providers often must have appointments back- to-back, every 15 minutes or even sooner. If it seems like the doctor is in a hurry to move on to the next appointment, you may be right. If you need more time, let him/her know and she should be willing to work this out often this can be done when making the appointment for your child.

Let the doctor get to know your whole child- Talk about the good things as well as your concerns. Share pictures and stories so he or she can appreciate and get to know your child.

Express gratitude- Say thank you, in person or in writing. Let your doctor or health provider know what is helpful and that he or she is doing a good job. You may be surprised how little they actually hear words of gratitude and appreciation.

Don't expect perfection- Every relationship has tense moments or bumpy times and so will this one. Be willing to make changes, if needed. Recognize that doctors and health providers are human, too, and give him or her the chance to make things better.

If you are mostly pleased with your child's doctor, then it is worth working through the rough times.

Practicing Good Communication with Your Doctor or Health Provider

A two-way conversation- Think of communicating with your doctor and health provider as having a friendly, respectful conversation. That means it is two-way and both of you should bring your questions, concerns, successes, and hopes to the conversation.

Get clear about how to communicate- Ask your doctor or health provider how to best communicate about your child's care.

Is there a good time during the day to call?

Does she or he prefer that you first talk to the office nurse if you have questions between appointments?

Are there ever situations when the doctor or health provider would want you to call him or her at home?

Does your doctor or health provider welcome communication via email? How about fax?

Practicing Good Communication with Your Doctor or Health Provider

Feel okay about needing advice between appointments-If you have a concern between appointments and feel that you need or want an answer from your child's doctor or health provider, ask the nurse to have him or her call you. Explain that you are more worried than usual - for reasons you may not be able to explain just yet - and that you would really appreciate talking directly to him or her.

Reflecting- Were you able to discuss your most important questions or issues? If not, is this okay with you or is there a plan for how you will get the information you need?

Did you feel like a partner in your child's health care team? Is there something you might want to do differently next time?

What If You Decide to Change Doctors or Health Providers?

Most parents are pleased with their child's doctor. But sometimes things just don't feel right. Here are some questions to ask yourself:

- 1) Does the way the office is run work for you?
- 2) Is the doctor available when you need him or her?
- 3) Are you often confused about recommendations and why certain treatments are prescribed?
- 4) Do you feel like your concerns are not taken seriously? Does this make you question and doubt your instincts, or your doctor's or health providers?

Trust your gut. If the relationship doesn't feel right and you haven't been able to make it better, then know that it is time to change doctors. Try to do it in a positive way.

Involving Your Child's Doctor in the Early Intervention Program or Other Services

Doctors and health providers are interested and want to be involved in a child's early intervention program and other services your child may receive. However, busy schedules can keep them from taking an active role.

If you make it a point to include your doctor or health provider in early intervention decisions and other service programs your child is receiving invite his opinion, you may find that you have created an Early Intervention Partnership and a good Family Professional Partnership.

Involving Your Child's Doctor in the Early Intervention Program or Other Services

Inform- Make sure that your doctor or health provider is on the mailing lists of all your child's programs and any family support organizations that you may be involved with. This will assist in being a resource for other families as well.

Bring reports that you especially want to discuss to appointments.

Be a link between the doctor and health provider, early intervention program and other services. Share questions and concerns back and forth.

Invite- Ask if he or she could ever attend an IFSP, IEP or other team meeting. Ask about best times and places.

Your doctor or health provider might be willing to attend meetings on days not scheduled for patients, in the early morning, or at the end of the workday. Holding a team meeting at your doctor's office may make it easier for him to be involved.

Getting the Most Out of an Appointment

Scheduling- Schedule the doctor or health provider's visit for the first appointment of the day or right after lunch if you would like to cut down on waiting time.

If you have questions or concerns that may take more time than usual, ask the office staff to schedule a longer appointment. Your doctor or health provider and staff will appreciate the advance notice and you will feel less frustrated about not having enough time.

Preparing- Think about what you would like to get out of the appointment ahead of time:

Make a list of your questions, concerns, and other information you would like to share.

It is okay to bring up things that don't seem related to health but still matter to you and your child.

Decide what on your list is the most important to you. Ask the doctor or health provider if he or she would like a copy of your questions and concerns ahead of time. Emailing, faxing, or dropping your list off before the appointment might give more time for the doctor or health provider to prepare more complete responses to your questions.

Participating- Share your list of questions and concerns at the start of the appointment. The doctor or health provider likely has his own list for what he needs to accomplish during this visit. Together you might need to decide what you discuss during this appointment and what you discuss at a later time.

Participating- Things can move so quickly during appointments that it can be hard to remember all that is said. Here are some ideas to help with remembering:

- ♥ Take notes. Use the same notebook to write down your questions and the answers at each appointment. This will make it easier to keep track of all the information over time.
- ♥ Bring someone along who can help listen and take notes and be there to support you, if needed.
- ♥ Ask if you can tape record your conversation.

Sometimes you might need to get the conversation back to your concerns. Here are some ways to do this:

- ♥ Ask a question. "What do you suggest about..."
- ♥ Tell a story about something going on in your child's life that you want to discuss. "The other day at the IFSP or IEP meeting..."
- ♥ Simply change the topic. "One other thing I would like to talk to you about is..."
- ♥ If your doctor or health provider gives you information that is difficult or hard to understand, ask if you can call him later to go over your questions.
- ♥ If your doctor or health provider can't attend the IFSP or IEP meeting, ask for recommendations and input ahead of time.

Share your doctor's or health provider's input with the IFSP or IEP team.

Your doctor or health provider can be your ally in helping you get the services you believe your child needs. Talk to him or her about what you think is needed. If your doctor or health provider agrees, ask him or her to write a letter to the IFSP or IEP team explaining your joint recommendations.

Ask your doctor or health provider if a team member can call him to discuss the recommendations.

Update- During well child visits or other appointments, tell your doctor about the progress your child is making in the early intervention or other service programs that your child receives. Ask any questions and share any concerns you have about the services.

Another fun and memorable way to update the doctor or health provider is to send an occasional picture of your child with a note highlighting his or her progress:



Being an Advocate

Do you value early intervention and other services that your child receives? Do you wish your child had been referred sooner? Do you think doctors and health providers need to know more about early intervention and other services? Do you want to be an Advocate?

Parents are often the most powerful advocates. You have the personal experience and the real life stories to share. you can make a difference.

Here are some simple steps you can take to spread the word about the importance of the services our children receive:

Who to talk to-Start with a group that is familiar and friendly - tell your family and friends about early intervention and any other services that your child receives and how it has helped your child and family.

Share this message with your child's doctor or health provider , and then offer to share your message with others in his or her practice.

Whether your child is in early intervention or in other services, if your interested in becoming more involved ask who you contact. Contact Family Voices of North Dakota and express your interest in being more involved and they can connect you as well.

If you enjoy public speaking, you might consider being on Parent Panels and making formal presentations.

What to say-Some people want to hear research findings on early intervention and other services. For most people, personal stories are what help us understand how a program makes a difference in the daily lives of children and families Stories are what move us to make a change for the better.

What stories or examples do you want to share that bring to life one or more of the following research points?

Early intervention and other service programs help families adapt and function-How does the help your child receives make a difference for your family? Does it ease some stress and worry? What have you learned that helps you feel good about your relationship with your child?

Early intervention and other service programs help children reach their potential-What are your hopes for your child? How has and how will early intervention and other service programs help? **The most effective programs begin early.** What was your earliest worry about your child? How did the doctor respond or how do you wish he had responded? Explain how a family organization or the FVND Health Information and Education Center helps families find services, resources, funding, and contact information.