

Building Early Intervention Partnerships With Your Child's Doctor:

Tips from and for Parents



WASHINGTON STATE
Department of
Children, Youth, and Families

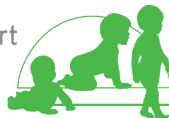
Early Support
for Infants
and Toddlers





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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 best qualities are and what she needs.

So when your child receives early intervention, 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, but you probably also want him or her to be involved. An "Early Intervention 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. This booklet gives suggestions and ideas for getting started with a new doctor and also for improving a partnership that you already have.

**For ease, the word "doctor" is used but these ideas could also be helpful with other primary care providers like nurse practitioners, physician's assistants, and others.*

Choosing a Doctor

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 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 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?

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

A doctor 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

Be a partner

Decide what type of partnership you want with your child's doctor. 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 are part of a team.

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

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 to be delighted with your child, then show your delight in your child.

Be understanding

Doctors 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 are probably right!

If you need more time, let her know and she should be willing to work this out. See *Getting the Most Out of an Appointment* for specific ideas on getting more time.

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 know what is helpful and that he or she is doing a good job.

Don't expect perfection

Every relationship has bumpy times and so will this one. Be willing to make changes, if needed. Recognize that doctors 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.

See Deciding to Change Doctors for information on when you might choose to make a change.

Practicing Good Communication

A two-way conversation

Think of communicating with your doctor 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 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 would want you to call him or her at home?

Does your doctor welcome communication via email? How about fax? Other operations?

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, 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

Deciding to Change Doctors

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

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

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.

"Thanks for all you've done for my child. We really appreciate the time you have spent with us. But right now this is not the perfect fit for our family – I would like my child to see someone else."

Involving Your Child's Doctor in the Early Intervention Program

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

If you make it a point to include your doctor in early intervention decisions and invite his opinion, you may find that you have created an early intervention partnership!

Here are some suggestions:

Inform

Make sure that your doctor is on the mailing lists of all your child's programs.

Bring reports that you especially want to discuss to appointments.

Be a link between the doctor and the early intervention program – share questions and concerns back and forth.

Invite

Ask if he or she could ever attend an Individualized Family Service Plan (IFSP) or other team meeting. Ask about best times and places.

Your doctor 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'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 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 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 to prepare more complete responses to your questions.



Participating

Share your list of questions and concerns at the start of the appointment. The doctor 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.

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 meeting...”

- Simply change the topic. “One other thing I would like to talk to you about is...”
- If your doctor 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 can’t attend the IFSP meeting, ask for recommendations and input ahead of time.

“This is what I am going to ask for in my child’s IFSP. What do you think?”

Share your doctor’s input with the IFSP team.

Your doctor 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 agrees, ask him or her to write a letter to the IFSP team explaining your joint recommendations.
- Ask your doctor 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 program. Ask any questions and share any concerns you have about the services.

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

“Here is my daughter having fun at dinnertime. In early intervention, I learned how to encourage her to eat more table foods. She doesn’t gag and cry at the sight of food anymore and I’m not so worried about her growth. Early intervention helped me have a better relationship with my daughter and helped my family, too – mealtimes are no longer a battle! Thanks for the referral!”

Being an Advocate for Early Intervention

Do you value early intervention? Do you wish your child had been referred sooner? Do you think doctors need to know more about early intervention? Do you want to be an Early Intervention 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 early intervention:

Who to talk to...

Start with a group that is familiar and friendly – tell your family and friends about early intervention and how it has helped your child and family.

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

Join your local County Interagency Coordinating Council. You will meet others who share your passion for early intervention. Ask your Family Resources Coordinator (FRC) how to join. If you do not have an FRC, you can call 1-800-322-2588

(Family Health Hotline) and ask for the lead FRC in your county.

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

What to say when presenting...

Some people want to hear research findings on early intervention. 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 helps 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 helps children reach their potential.

What are your hopes for your child? How has and how will early intervention help?

The most effective early intervention 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 FRC helps families find services, resources, funding, and contact information.

The most effective programs involve parents.

How are you involved? What do you like about it?

The important message: Early intervention works for children and families so *Please Ask, Babies Can't Wait.*

FOR MORE INFORMATION:

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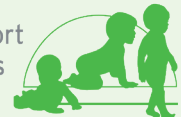


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