

 **Don't give up:**

If you have not found what you think your child needs, either in a provider or in seeking financing for a specific treatment or equipment, don't give up. Recognize that many times "no" is the first response, but on further investigation, "no" can be turned to "yes" with the right documentation, gathering more information or speaking or working with another individual.

———— *Help Your Provider Help Other Families* ————

 **Provide feedback to your child's providers:**

Let your child's providers know both when you appreciate their efforts and when you are not satisfied. Write a note, or tell them in person. Be as specific as possible so that the information can help improve your child's care as well as the care of other children.

 **Share information and resources:**

Your provider may have a bulletin board or other method for sharing information with parents. Offer to share notices about meetings, parent groups or community resources. Let your provider know that they can share your contact information if you are willing to speak with other families of children with special needs.

 **Offer to provide input beyond your child's specific needs:**

Many providers routinely seek the input of families in their practice to help them improve the services they provide. Ask if there is a Family Advisory Group in the clinic, doctor's office, or hospital setting where your child is treated. Such groups of families meet together with providers and staff and provide feedback about how policies meet the needs of families and children. If such a group exists, you might become a participant. If an Advisory Group does not yet exist in your provider's setting, you might suggest starting one.

Family Voices, Inc.
2340 Alamo SE, Suite 102, Albuquerque, NM 87106
Tel: (888) 835-5669 Fax: (505) 872-4780
Internet: www.familyvoices.org
NW287

FAMILIES PARTNERING WITH Providers

Tips to Help Families Build Effective Partnerships
with their Child's Health Care Providers



Family Voices is a national grassroots organization with a network of families and friends in every state, speaking on behalf of children and youth with special health care needs. Family Voices believes that strong family-professional partnerships improve decision-making, enhance outcomes, and help to ensure quality health care for children and youth with special needs.

FAMILY VOICES®

February, 2007

As your child's most consistent caregiver, **you know your child with special health care needs (CYSHCN) in ways that no one else does.**

You want to be sure that your child's health care needs are met. Your perspective when something is wrong with your child, or how he/she is responding to a treatment or medication are critical pieces of information that you want to effectively share with the providers who treat your child. Through clear communication between you and your child's doctors and other providers, you can develop partnerships that will help your child receive the best kind of health care. The following tips about preparing for an office visit, talking with your child's provider, learning more after the visit, and partnering in other ways will help you work with your child's health care providers to ensure that your child and perhaps others, as well, receive the highest quality health care.

Preparing For An Office Visit

Trust your instincts:

When you first suspect that something is not right with your child's health, or when your child is first diagnosed with a special health care need, you may not realize how valuable your instincts and intimate knowledge of your child are to his/her medical care. What you know and see about your child is critical to share with health care providers. Rely on your own good sense to know when to seek more information. Never be reluctant to check with your child's provider when you have a question about how your child is doing, how a medicine is working, or what to expect during a treatment.

Seek all the information that you can:

Your child's providers will be your important first source of information about his/her health care needs and care. There are also many additional sources of information about specific diagnoses, medicines, and potential treatments that your child's providers and others can help you find. You may find helpful information from national and local diagnosis-specific organizations, on the web, through other parents, in the library, and through books. Share what you learn with your child's providers to find out more about how this information might apply to your child.

This publication has been developed through the National Center for Family Professional Partnerships project, a cooperative agreement with the Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau (HRSA 5-U40-06-002).

Maintain a file of important information about your child:

Ask to read your child's medical records. Keep copies of important records in your own files. Ask for a copy of the report after your child visits a specialist. Make your own notes on how your child responds to treatments or medications and what medications/doses they take, and be prepared to share this information with providers. Along with health records, it can be helpful to save other information such as appointment dates, school information, emergency contacts, and other information in a single notebook. This information will then be in one handy place and can be of vital importance to share with providers, particularly in the case of an emergency. Many providers and health systems are now using electronic records, some of which allow families to include their own notes in the record. There are also special computer programs to help you track your child's medical information.

Ask for second opinions and referrals when you think you need them:

You may want to seek out more than one doctor's opinion before proceeding with a specific treatment that has been suggested or when you are not comfortable with a provider's approach or suggested treatment. Most providers are happy to provide such a referral to a "second opinion."

Change providers if you cannot work out a way to feel satisfied:

Many times differences of style or other difficulties between families and providers can be worked out over time. However, if you have not been successful in building a helpful partnership with a provider, seek out another provider that better fits your needs. Tell the provider that you are leaving why you want to change. Your input may help the provider work with other families in the future.



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specific diagnosis or may provide you with too many possible diagnoses. Discuss your concerns about diagnosis with your child's providers and seek more information if you do not understand the responses you receive.

Ask your provider for a written care plan:

Ask your provider to write down his/her recommendations in a written care plan. Such a plan can help you to understand your child's needs and the provider's suggested treatments. It can help you plan for your child's future and help you share information with others such as home care, day care or school providers.

Ask for help in financing your child's care:

One of the critical issues that families face is finding ways to pay for their child's medical care. A good partnership with your child's provider can help. Find out as much as you can about your child's health coverage plan/s, and give this information to your child's providers. Getting appropriate documentation and paperwork from your provider may avoid delays in processing insurance payments. If the suggested treatment or equipment is unusual, ask the provider's staff to help find out how the medical necessity for this treatment has been documented in other cases. Ask for help in getting information about and applying for public programs that might help your child.

———— *Learning More* ————

Make contact with another parent or parent group:

Many parents find that speaking to other parents provides them with a great deal of helpful information, comfort and support. Another parent may have useful information about how they have handled various situations or special needs, may recommend questions to ask of your providers, or recommend specific providers or programs. Seek out a parent organization such as a Family-to-Family Health Information Center* in your state to find another parent to speak to, or a parent group that can offer resources, information and support.

* For more information contact Family Voices, the National Center for Parent - Professional Partnerships: (www.familyvoices.org/info/ncfpp/f2fhic.php) or (888) 835-5669.

Search for providers that meet your needs:

While some providers enter a family's life suddenly in an emergency, most of the time parents are able to choose their child's providers, within the limits of their health plans and provider availability. Most health plans and systems now require that a child have a primary care provider who is responsible for overseeing all of his/her care, including well care, referral to specialists and coordination of care and services, including community based services. This approach is called a "Medical Home*." In order to find providers that meet your own and your child's needs, ask other families for their recommendations. Check out a provider's knowledge and experience with your child's specific needs. Ask providers about their views on parents being present for treatments and taking a shared role in decision making. Seek providers with whom you and your child feel comfortable and who you feel will understand your family's customs and culture.



Ask for special consideration if needed:

Let your provider know what works best for your child. If specific things help your child cope or particularly frighten your child, tell your provider. This information can help the provider relate to your child. A provider might be able to make an exam or treatment easier for your child by knowing his/her special interests, activities and family events. If your child is particularly vulnerable to other children's infections, you might want to ask to wait in a special area for your appointment rather than a general waiting area. Tell your provider about your customs and beliefs that may effect recommended treatments. Speak up if a schedule is recommended that conflicts with your special plans or holidays. It might be possible to reschedule.

"...Parents know the needs of their child best. They are with them 24 hours a day, 7 days a week. We need to be comfortable with the doctors we need for our child's care in order to obtain appropriate equipment and services."

"What Do Families Say About Health Care for Children with Special Health Care Needs?"
<http://www.familyvoices.org/pub/projects/NationalFamrpt.pdf>

*"In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met." Academy of Pediatrics (<http://www.medicalhomeinfo.org/>).

 **Look for ways that other family members can participate:**

If only one family member builds a relationship with a provider, the other parent or family members will miss important opportunities to understand the child's health care needs. Try to have more than one parent or important family member participate in key appointments, at least some of the time. If this isn't possible, try to bring a close friend or neighbor. Two people will likely remember different information from the appointment and can talk over what they heard after the appointment.

————— *Talking With Your Child's Provider* —————

 **Communicate openly with your child's providers:**

Communication is critical in your relationship with your child's providers. Be open and honest. Speak up if you do not understand enough about a specific treatment or need further information. Make a list of questions that you'd like to ask your child's providers at visits or over the phone or e-mail. Put the most pressing questions at the top of the list. Find out what times and what ways work best to communicate with the provider. Be direct when sharing your perceptions, observations or concerns. Think about when you need to speak privately with the provider and ask for that opportunity. Be sure that your child also has the opportunity to speak privately with his/her providers.

 **Help your child build a relationship with his/her providers:**

Your child with special health care needs will likely have a great deal of experience over time with health care providers. It will help your child to receive the highest quality care and to become as independent and healthy as possible if you help them take a role in their own health care as early as possible. Help them write down their questions for their providers. Encourage them to speak for themselves to the best of their ability. Choose providers who listen to, understand and respect your child.

"Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive."

Maternal and Child Health Bureau

<http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

 **Ask every question that you wonder about:**

If you aren't satisfied with the response, ask again, or ask someone else. You can ask the same question of a number of providers in order to learn more about your child's needs. It may help you understand if you hear the information more than once. Every question that you have is important. Don't be afraid to ask. And don't be afraid to ask again.

 **Don't be intimidated:**

Sometimes family members feel hesitant when talking with health care providers because of a provider's medical credentials or experience. Providers do indeed have specialized expertise. That is why we seek their medical care. As your child's parent, you too, and your child, have special expertise. You and your child have critical pieces of the information needed to help your child receive the best health care.

 **Ask your child's providers to recommend articles or books:**

If you find it helpful to learn more information by reading, ask your child's providers to help you find helpful written materials. Ask if there are conferences or meetings where information about your child's diagnosis is going to be discussed. In turn, share with your child's providers the information and resources that you find. Ask questions about what you've read.

 **Ask if you may tape a conversation with a provider:**

Some visits to providers can be very stressful, especially if you are seeing a specialist for the first time or if you are seeking a diagnosis. It may be difficult later to remember what you've heard. If the provider has no objections, tape the conversation. This can help you remember and review at a later time what was said. If taping is not an option, take notes.

 **Recognize that it may take time to get a diagnosis:**

Every child is an individual, and in some cases his/her special needs may be hard to identify and name. Many children have multiple special needs or symptoms that are not easily categorized. Your provider may be reluctant to provide a