TIPS Caring for a Child with Special Health Care Needs

Partnering with Your Child's Provider

AS YOUR CHILD'S MOST CONSISTENT CAREGIVER, you know your child/youth 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. You need to share what you know with the providers who treat your child. Tell them if something is wrong with your child. Let them know how your child responds to a treatment or medication.

You can develop partnerships with your child's doctors and other providers. These **partnerships will help your child receive the best healthcare.** Start with clear communication between you and providers. Be sure to share your cultural differences so that they do not become barriers to access and service. The following tips will help you prepare for an office visit, talk with your child's provider, and learn more after the visit.

PREPARING for an OFFICE VISIT

TRUST YOUR INSTINCTS

Your instincts and intimate knowledge of your child are critical to his/her medical care. Share what you know and what you observe with health care providers. Call when you see a problem. Providers rely on the information you give.

Never be reluctant to ask a question about how your child is doing, how a medicine is working, or what to expect during a treatment.

Call your child's doctor nurse before an appointment if you have specific concerns, so they are aware ahead of time. Nurses are great mediators and can be very helpful both to the family and the doctor.

SEEK ALL THE INFORMATION THAT YOU CAN

There are many sources of information about diagnoses, medicines, and treatments. Talk with your child's providers. Check out national and local organizations on your child's diagnosis. Talk with other parents. Find information on the web, in the library, and through books.

Share what you learn with your child's providers.

PREPARING for an OFFICE VISIT

SEARCH FOR PROVIDERS THAT MEET YOUR NEEDS

Most health plans now require that your child have a primary care provider. This provider is responsible for overseeing all of your child's care. S/he provides well care, referrals to specialists, and coordination of care and services. This approach is called a "**medical home.**"

Find providers that meet your family and child's needs. Ask other families for recommendations. Check out a provider's knowledge and experience with your child's needs. Hospital websites often post a provider's background and expertise online. Talk to providers about your role in shared decision making. Be sure they will understand your family 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.

If your child gets sick easily, ask to wait in a special area for your appointment.

Tell your provider about your customs and beliefs that may affect recommended treatments.

Speak up if an appointment date conflicts with your special plans or holidays.

LOOK FOR WAYS THAT OTHER FAMILY MEMBERS CAN PARTICIPATE

Try to have more than one parent or family member participate in key appointments. If this isn't possible, try to bring a close friend or neighbor.

Two people will likely remember different information from the appointment. They can talk over what they heard after the appointment.

A family-centered MEDICAL HOME is not a building, house, hospital, or home healthcare service, but rather an approach to providing comprehensive primary care. In a family-centered medical home the pediatric care team works in partnership with a child and a child's family to assure that all of the medical and non-medical needs of the patient are met. Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community services that are important for the overall health of the child and family. See http://www.medicalhomeinfo.org/.

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national grassroots network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

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TALKING with your CHILD'S PROVIDER

COMMUNICATE OPENLY WITH YOUR CHILD'S PROVIDERS

Communication should be open and honest. Speak up if you do not understand a specific treatment or need further information. Be direct in sharing your perceptions or concerns.

Make a list of questions that you'd like to ask your child's providers at visits or over the phone or e-mail. Prioritize the questions.

If you need to speak privately with the provider, 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

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.

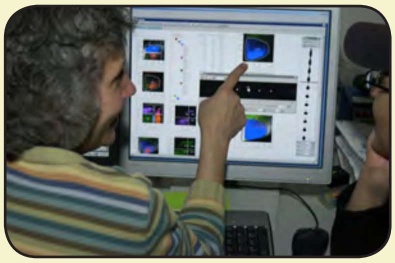
Help them write down their questions for their providers. Encourage them to speak for themselves to the best of their ability. Choose providers who listen to, understand and respect your child.

ASK EVERY QUESTION THAT IS ON YOUR MIND

If you don't understand a 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.

DON'T BE INTIMIDATED



Sometimes you may feel hesitant when talking with health care providers because of their medical credentials.

They do have specialized expertise. But you and your child also have special expertise. Your child's provider can learn from you and your child.

FAMILY VOICES STATE AFFILIATE ORGANIZATIONS (SAO) and/or FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2F HIC) can help you communicate with your child's provider. These resources, which exist in every state and the District of Columbia, are staffed by family members who have first-hand experience navigating the maze of health care services and programs for children/youth with special health care needs. This intimate understanding of the issues that families face make support staff exceptionally qualified to help families navigate health systems, partner with their child's provider, and make informed decisions regarding the health of the child. Find the F2F in your state at: http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/. Find the Family Voices SAO at http://www.familyvoices.org.

Like their peers, children with special needs deserve every opportunity to enjoy a happy and healthy childhood at home in their communities. Families equipped with reliable, accurate information about ways to support their child's health, education and social development will help them grow into productive adults as defined by their personal, family and community cultural beliefs and values.

TALKING with your CHILD'S PROVIDER

ASK FOR ADDITIONAL READING MATERIAL

Your child's providers may help you find additional information. Ask if there are conferences that you might go to where information about your child's diagnosis is going to be discussed. In turn, share what you learn with your child's provider.

ASK TO TAPE A CONVERSATION

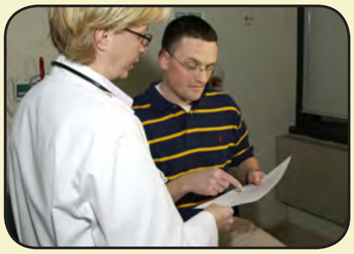
Sometimes, it is difficult after the appointment to remember what was said. If the provider has no objections, tape the conversation. If taping is not an option, take notes.

A DIAGNOSIS MAY TAKE TIME

Many children have special needs or symptoms that are hard to categorize. Your provider may not feel that they can give a specific diagnosis. They may give too many possible diagnoses. Discuss your concerns about diagnosis with your child's providers. Seek more information if you do not understand.

ASK FOR A WRITTEN CARE PLAN

Ask your provider to write down his/her recommendations in a written care plan. 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

Find out as much as you can about your child's health coverage plan/s. Give this information to your child's providers. Get the documentation and paperwork you need from your provider. This may avoid delays in processing insurance payments.

If the suggested treatment or equipment is unusual, ask for help with your insurance company.

Ask for help in getting information about and applying for public programs that might help your child.

Family Voices National Center for Family/Professional Partnerships (www.fv-ncfpp.org) has resources to help you learn more about family-centered care (FCC), including

- *Family-Centered Care: From Theory to Practice: a 1-pager that defines FCC, discusses the benefits of FCC, and provides guidelines for families*
- *Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review: a research article summarizing the evidence of FCC*
- *Family-Centered Care Tool: a quality measurement tool developed by Family Voices in partnership with expert university researchers that can be used by providers to improve family-centeredness ot their practice*

Because families are at the center of a child's life, they must be equal partners in decision-making and all aspects of the child's care. Family-centered care is community-based, coordinated, culturally and linguistically competent, and guided by what is best for each child and family.

LEARNING MORE

LEARN FROM OTHER PARENTS

Talking to another parent can help. **The Family to Family Health Information Center** in your state is a free resource. They can provide information. They can also connect you to another parent for support.

MAINTAIN A FILE OF IMPORTANT INFORMATION

Ask for and keep copies of your child's records. Keep these records in a **Care Notebook**, along with appointment dates, school information, and emergency contacts.

Include information on how your child responds to treatments or medications. Keep track of their medications and doses.

Summarize key information before an appointment and refer to the **Care Notebook** if needed

Many providers use electronic records. Sometimes you can add your own notes in these records.

SEEK SECOND OPINIONS IF NEEDED

You may have questions about a suggested treatment. You may not be comfortable with your provider's approach. Ask your provider for a referral for a "second opinion."

CHANGE PROVIDERS IF NEEDED

If you have not been successful in building a positive partnership with a provider, make a change. Find another provider that fits your needs. Tell the provider that you are leaving and why you want to change. Your input may help the provider work with other families in the future.

DON'T GIVE UP

If you have not found what you think your child needs, don't give up. Many times, "no" is the first response. But "no" can be turned to "yes." Get more documentation. Gather more information. Speak or work with another individual.

A CARE NOTEBOOK is a tool that can help you organize important information about your child. Bring the notebook to appointments and meetings, so you can easily share information with doctors, therapists, and school or child care staff. A Care Notebook can help you: 1) Keep track of your child's medicines or treatments; 2) Organize phone numbers for health care providers and community organization; 3)Prepare for appointments; 4) File information about your child's health history; 5) Share new information with your child's primary doctor, public health or school nurse, and others caring for your child.
http://cshcn.org/planning-record-keeping/care-notebook

HELP YOUR PROVIDER HELP OTHER FAMILIES

PROVIDE FEEDBACK

Tell your provider when you appreciate their efforts. Let them know when you are not satisfied. Write a note or tell them in person. Be specific so that the information can help improve services for your child and others. The **Family Voices' Family- Centered Care Assessment Tool** may help you and your provider work together.

SHARE INFORMATION

Share notices about meetings, parent groups or community resources with your provider. This will benefit other families. Are you willing to speak with others? Let your provider know that they can share your contact information.

GET INVOLVED

Ask if there is a Family Advisory Group where your child is treated. Such groups of families meet together with providers and staff. They 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.

WHAT ARE THE QUALITIES OF A FAMILY/PROFESSIONAL PARTNERSHIP?

1. **Respect:** The family and provider regard each other with esteem and demonstrate that esteem through actions and communications.
2. **Communication:** The quality of communication is positive, understandable, and respectful among all members at all levels of the partnership. The quantity of communication is also at a level to enable efficient and effective coordination and understanding among all members.
3. **Commitment:** The family and provider share a sense of assurance about (a) each other's devotion and loyalty to the child and family, and (b) each other's belief in the importance of the goals being pursued on behalf of the child and family.
4. **Equality:** The family and provider feel a sense of equity in decision making and service implementation, and actively work to ensure that all other members of the partnership feel equally powerful in their ability to influence outcomes for children and families.
5. **Skills:** The family and provider perceive that others on the team demonstrate competence, including service providers' ability to fulfill their roles and to demonstrate "recommended practice" approaches to working with children and families.
6. **Trust:** The family and provider share a sense of assurance about the reliability or dependability of the character, ability, strength, or truth of the other members of the partnership.

Dimensions of family and professional partnerships: Constructive guidelines for collaboration by Blue-Banning, M., Summers, J., Frankland, H. C., Nelson, L., & Beegle, G., Exceptional Children, Volume 70, No. 2, 2004, 167-184.

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