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Working With Children With Special Health Care Needs:

*What families want health care
providers to know*

*Health Care For All Children's Quality Initiative,
Federation for Children with Special Needs
With funding from the Nathan Cummings Foundation*

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About Health Care For All

Health Care For All is dedicated to making adequate and affordable health care accessible to everyone, regardless of income, social or economic status. Our goal is to empower consumers in Massachusetts to know more about the health care system and become involved in changing it. We are particularly concerned about the most vulnerable members of society -- the uninsured, low-income, elders, children, people with disabilities and newcomers to the country. Our work combines policy analysis, information and referral, advocacy, community organizing and public education.

**For more information, please contact Health Care for All
30 Winter Street 10th Floor / Boston MA 02128
(617) 350-7279 / www.hcfama.org**

About the Federation for Children with Special Needs

The Federation for Children with Special Needs is to provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

**For more information, please contact the Federation
for Children with Special Needs
1135 Tremont Street Ste. 420 / Boston MA 02120
(617) 236-7210 / www.fcsn.org**

Resources on Cultural Competence & Diversity in Health Care

CultureMed

CultureMed is part of the SUNY Institute of Technology. It is a website promoting culturally competent health care for refugees and immigrants.
www.sunyit.edu/library/html/culturemed/

Ethnomed

This site contains information about cultural beliefs, medical issues, and related issues pertinent to the health care of recent immigrants.
www.ethnomed.org

National Center for Cultural Competence

This site is designed to increase the capacity of health care and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.
www.georgetown.edu/research/gucdc/nccc/

The Provider's Guide to Quality and Culture

This guide is produced by Management Sciences for Health and is designed to assist health care organizations in providing high quality, culturally competent services to multi-ethnic populations. The site provides information on cultural groups, health disparities, and improving patient-provider interactions.
<http://erc.msh.org/quality & culture>

Resources for Cross-Cultural Health Care

This site provides resources for health care providers and consumers about language and cultural competence in health care and provides tools to design better programs and policies.
www.diversityrx.org

Dear Provider,

Some 12.8 million children in the United States have some form of special health care need. Moreover, the majority of these children require multiple services to meet their needs¹, thus making coordinated care and positive working relationships between you and the families of these children all the more important.

This guide is designed to help you better care for your patients with special health care needs – to build effective relationships with them and their families, and to achieve the best medical outcomes possible.

The suggestions in this guide come directly from parents of children with special health care needs. The ideas come primarily from comments made during focus groups with these parents.

We hope that you will find this guide useful and informative in your work providing care to children with special health care needs and their families.

Children with special health care needs include all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type and amount beyond that required by children generally.²

*~ Maternal & Child
Health Bureau*

This guide was written by Stacey Auger and Denise Lau with assistance from Barbara Popper, Lucy Meadows, and Barbara Donati.

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What Families Believe

While acknowledging the invaluable role that health care providers play in their child's care and everyday lives, families stress the importance of being recognized by physicians and other health care providers as their child's most important caregiver. An understanding of this underlying belief will help you establish effective communication with the child and his/her parents.

Key Findings from Focus Groups

- ✧ Communication between patients, families, and providers is essential.
- ✧ Families want better communication and coordination among all of the health care providers involved in their child's treatment and care.
- ✧ Families want their health care providers to know and share information regarding new research findings on their child's condition.
- ✧ Patients, families and providers may unintentionally erect barriers due to language, culture, and / or educational differences.

The Family-Centered Philosophy

The family-centered philosophy of service delivery focuses on the crucial role of the family in the healthy development of children.

According to Allen and Petr, "Family-centered service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully-informed choices made by the family and focuses on the strengths and capabilities of these families."³

Online Resources

Resources on Special Health Care Needs

Disability Resources on the Internet

Information and services for children with disabilities and their families. Includes a guide to disability resources on the internet, and state-by-state guide to disability related organizations and government agencies.
www.disabilityresources.org

Family Village

A global community that integrates information, resources, and community opportunities on the internet for people with mental retardation and other disabilities, their families, and those that provide them services and supports.
www.familyvillage.wisc.edu

Family Voices

A national, grassroots clearinghouse for information and education concerning the health care of children with special health needs.
www.familyvoices.org

Federation for Children with Special Needs

Provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities.
www.fcsn.org

National Information Center for Children & Youth with Disabilities

Provides information on disabilities and disability related issues.
www.nichcy.org

National Organization for Rare Disorders

A federation of voluntary health organizations serving people with rare disorders and disabilities.
www.rarediseases.org

New England Regional Genetics Group

A broad based consortium promoting the use of high quality human genetic services and encouraging activities in genetic education.
www.nergg.org

References

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- ⁵ National Information Center for Children and Youth with Disabilities. *A Parent's Guide to Doctors, Disabilities, and the Family*. 1990; Vol. 1, No 2.
- ⁶ Center for Effective Collaboration and Practice (<http://cecp.air.org>).
- ⁷ Hickson GB, Stewart DW, Altemeier WA, Perrin JM. *First Step in Obtaining Child Health Care: Selecting a Physician*. 1988; 81: 333-338.
- ⁸ National Information Center for Children and Youth with Disabilities. *A Parent's Guide to Doctors, Disabilities, and the Family*. 1990; Vol. 1, No 2.

Why Effective Communication Is Important

As in any relationship, patients, families and health care providers must first feel comfortable with one another before they can begin communicating openly and honestly.

Until they learn to trust and feel at ease with their health care providers, patients and families may:

- ✧ Feel or sense that they are wasting the providers valuable time;
- ✧ Omit details of their history which they deem unimportant;
- ✧ Hesitate to mention things they think will place them in an unfavorable light or embarrass them in some way. This may include embarrassment over their type or lack of health insurance, any social issues or problems, language limitations, inability to read, or their medical situation;
- ✧ Not admit that they don't understand medical terminology; or
- ✧ Believe the provider is not really listening and, therefore, does not have the information needed to make good treatment decisions.



The following pages provide tips and suggestions on working to overcome these barriers.

Open the Lines of Communication

Effective communication between patients, families and health care providers contributes to positive medical outcomes.

In order to establish and maintain open communication, there is great need to build trust and honesty. Patients, families, and providers each have roles to play in this process.

Patients and families need to:

- ✧ Recognize that a provider's experience and wisdom can be their best source of education;
- ✧ Recognize the time constraints clinicians face; and
- ✧ Understand both the possibilities and limitations of modern therapeutic capabilities.

Health care providers need to:

- ✧ Understand the family's standards regarding quality of life and their expectations of treatment; and
- ✧ Take steps to gain the trust of the patient and family so as to ensure compliance with the course of treatment.

The Need for Honest Dialogue... What Parents Say

Parents in focus groups reported their frustration with providers who shied away from explaining issues and diagnoses:

*"A doctor gives a worst case scenario to soften any unpleasant news."
~ focus group participant*

*"Doctors don't want to say your child is autistic."
~ focus group participant*

*"The doctor, a geneticist, did not explain the disorder – he just said it 'was not fatal.' The nurse ran out after me and gave me the information about [the National Organization of Rare Disorders]."
~ focus group participant*

Conclusion

Working with children with special health care needs and their families can be rewarding and gratifying, but it is not without its challenges. Viewing the patient and his or her family as partners is crucial to developing a strong positive relationship.

Openness and honesty help build the foundation for a working relationship where each person sees the other as a partner working towards the same goal: achieving optimal health for the child.

We hope that this guide has provided you with a framework to better understand the needs and concerns of children with special health care needs and their families.

Thank you for your commitment to these children.



What To Do When the Relationship Frays

Regardless of your best efforts, there will be times when you encounter a patient whose needs or demands strain a partnership that you have worked diligently to establish. Many times, an honest discussion with the patient and family about your relationship will resolve misunderstandings. There may be times, however, when no agreeable compromise can be reached.

Since you may not legally abandon patients, it may be worth discussing with the patient and family the option of being referred elsewhere. If this is the course of action that you, the patient, and the family decide to take, it would be most beneficial for you to provide the family with the resources they need to locate new care, and whenever possible to initiate contact with their new provider.

Putting them on the right path

Your patient's new provider will need information from you about their care and treatment. Be sure to forward medical records and pertinent information along to him or her. Additionally, it will be useful if you can help your patient and his or her family to prepare a list of questions to ask and information to share with the new provider. This will help the new provider and promote an easier transition for the family.

What Works Best in Communication

An effective therapeutic plan can best be created through open, two-way communication and a caring relationship. There are several steps you can take to help open these lines of communication.

Parents recommend that health care providers try to:

- ❖ Attend to patient comfort at all times.
- ❖ Establish and maintain eye contact.
- ❖ Show attention by using nonverbal clues such as nodding.
- ❖ Acknowledge and legitimize feelings of the patient and family.
- ❖ Ask explicitly if there are other concerns or remaining questions.
- ❖ Recognize the possibility of any cultural barriers.
- ❖ Arrange for medical interpreters in advance.

What Parents Say:

We feel respected when you...

Listen without interrupting.

Hear us for who we are as people.

Realize that sometimes we are intimidated by the medical culture and may not respond as fast as you would like.

Take time to clarify anything we say that you don't understand.

Explain what you're doing in an exam as you go.

Giving Families The Information They Need

Giving specific kinds of information to both new and established patients and their families will help build trust and cooperation. Sharing age-appropriate information in a non-threatening or frightening manner is greatly appreciated by families.

With new patients and families,

- ✧ Explain your experience working with children with special health care needs.
- ✧ Explain how your appointments are generally set up – How much time do you allot for each visit? Can families schedule extra long appointments?
- ✧ Explain who will see the patient and family when you are not available. Also explain the on-call schedule for night and weekend care.
- ✧ Inform the patient and family which hospital(s) you use for hospitalizations and hospital tests.⁴



Simple steps office staff can take

Often children with special health care needs have difficulty waiting and sitting patiently in an office. This can cause disruption and stress for the staff, the parents, and other patients.

Whenever possible, make accommodations in appointment scheduling for children with special health care needs. Inquire about the patient's needs and try to make every effort to schedule appointments when:

- ✧ there is a likelihood of little or no waiting time, such as first thing in the morning or immediately after lunch.⁸
- ✧ the clinician will be able to spend adequate time with the patient and family.

Making such accommodations will reduce tension at visits and strengthen relationships between staff, patients, and families.



Get your staff involved

Your patient's health care experience begins the moment he or she enters your office. While your interaction is important, so too are patient and family interactions with your staff and colleagues. Make sure your staff, and whenever possible, your colleagues, are educated about your patient's needs, concerns, and culture.

Studies show that good patient-provider relationships have a positive effect on both the management of long-term conditions and on the outcomes of health care. This is especially important to children with special health care needs.

Family—Staff Interactions

When asked why they had changed pediatricians, the second most common reason given by parents in a California study, was that they believed the office staff of their child's doctor were rude or unconcerned.⁷



With all patients and families,

- ✧ Explain whether or not you can make a diagnosis at the time of the visit.
- ✧ When recommending treatment, explain what steps should be taken immediately and what steps should be taken over the next few days and weeks.
- ✧ Whenever possible, explain how long a condition or illness is expected to last and when the child can be expected to feel better.
- ✧ Explain indications that the child is getting better as well as symptoms and complications to monitor that would indicate the child's condition or illness is getting worse.
- ✧ Provide the family with information on what to do and/or whom to call if the symptoms persist or if the child's condition worsens.
- ✧ Explain any long term concerns or needs.
- ✧ When appropriate, tell the family if you would recommend they seek a second opinion or see a specialist.⁵

Beware of Medical Terminology

When working with families, speak to both patients and parents in an understandable and comfortable manner. Remember that patients and parents may not necessarily understand medical terminology. If you do need to use such terminology, fully explain all aspects of the condition or diagnosis and make sure that what you have said is understood.

Making the Relationship Work

Recognize individual needs and strengths

First and foremost, it is most helpful for you to view the child in your care as an individual. Each child needs to be treated on an individual case-by-case basis. Understanding that children with special health care needs have exceptional issues and needs that require individualized attention and services is critical.

Just as you view the child as a whole person, it is equally helpful for you to view the family as a whole unit. Rather than emphasizing the disability, it is most helpful to empower the patient and family to make decisions about their own lives.

Ask the patient first

When children are accompanied by a parent to an appointment, clinicians often address questions to the parent. Try asking the child how he or she is feeling before addressing the situation with the parent. Children know how they are feeling—physically, emotionally, and mentally.



Cultural Competence

Cultural competence is defined as a set of congruent behaviors, attitudes, and policies that enable a system, agency, or group of professionals to work effectively in cross-cultural situations. Another definition is that cultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services; thereby producing better outcomes.⁶

Cultural Norms, Treatment and Care ... one parent's view

"There are differences between the medical care in the US and Brazil regarding diagnosis and treatment. [I] think that in the US more time is needed to diagnose due to legal issues. It is good if you have all of your previous medical information for the evaluation. After the evaluation in the US there is treatment but what is done in the previous country is ignored and [doctors] only address the issue as that is typical for the US. Cultural differences do not seem to be considered for evaluation and treatment.

~ focus group participant

Know the culture of the families you care for

Because beliefs and values vary from culture to culture, and have tremendous influence on behaviors affecting health, it is helpful for you and your staff to familiarize yourselves with a family's culture. Being knowledgeable about a patient's culture, as well as the differences that exist between their culture and your own, will help you to recognize and respond to any barriers that arise.

Language barriers also need to be taken into consideration. It can be risky to make assumptions about the languages which the patient and family speak, understand, and read; it is helpful to ask about this specifically .

Provider-patient encounters may become strained when patients cannot clearly explain symptoms and interpreters are not available or medically trained.

Whenever possible, therefore, try arranging for medical interpreters and ensuring that interpreters have enough training to be effective. Consider inviting a bilingual adult family member to the visit when an appropriate medical interpreter is not available.

By encouraging and allowing the child to answer your questions, you are offering him or her the opportunity to voice their feelings—a crucial part in your relationship. Communication will succeed when you truly 'hear' the concerns and viewpoints of the patient and respond to them.

Understanding the spoken and *unspoken* feelings, concerns, and hesitations of the child takes time but it is imperative for building the good relationship that will make your care more efficient.

Regardless of whether the child or the parent asks a question, answering questions adequately gives the child a sense of control and involvement while at the same time educating him or her about their care and treatment needs.

Listen to the parents

In the same way that you engage the child, it is also important to listen to and acknowledge the views and concerns of the family. As the primary caregivers, parents are reliable partners concerning their child's specific needs. The family will appreciate your and your staff's respect for this caregiving role.

Help families help you

In forming a partnership with the children and families in your care, sharing information is key. Ask patients and parents for the information you need to know. You can also suggest questions that they can ask of other specialists whom they consult.

Parents hold a great deal of knowledge about their child's condition, growth and development, behaviors, and reaction to treatment. Parents are the ones who see their children "in action." Encourage them to record this information and to share it with you and their other health care providers.

Capturing Parental Knowledge

Many families reported success with these ideas:

- ✧ Keeping a log of their child's symptoms.
- ✧ Keeping a narrative with them at all times of the appointments and treatments the child has undergone in the past in case they need to see a new provider.
- ✧ Bringing along a packet of information on their child's disorder when they are meeting or working with a new provider.
- ✧ Suggesting that a case conference about their child be held with all providers in the practice so that all are familiar with the child's case.

Give families the tools they need to prepare for working with you

Family Voices at the Federation for Children with Special Needs has created several Bright Futures for Families tools that you can share with the families you serve.

The ***Health Care Visit Checklist for Children with Special Health Care Needs*** helps families prepare for health visits so they can develop a good relationship with their child's health care provider. The checklist provides a list of questions parents should look for and ask when securing health care for their child. The checklist includes: 'Choosing a health care provider; Preparing for a health visit; During the visit; and After the Visit is Over.'

Available for download and ordering at www.brightfuturesforfamilies.org

The ***Family Pocket Guide: Raising Healthy Infants, Children, and Adolescents*** provides families with information on choosing and working with a health care provider; child growth and development from birth to age 21; what happens at each health care visit; and what to expect as children get older.

Available for download and ordering at www.brightfuturesforfamilies.org

Family Voices at the Federation for Children with Special Needs also recommends using '**Encounter Forms**' which are designed to be used by families and professionals, and which provide a shared framework that fosters partnership in health promotion and health supervision. Forms are tailored to the child's age and include the following sections: 'At today's visit; Things you and your child may want to discuss during the visit; Things to keep in mind between now and your next visit; How to prepare for the next visit, and What to expect at the next visit.'

Available for download at www.brightfutures.org/familymaterials