



Working Effectively with Doctors:

Your Guide to Better Care for Your Special Needs Child

Presented by: Advocates for Justice and Education, Inc., D.C. Parent Information Network
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Objectives

- To provide tips and tools for creating positive working relationships between families and doctors and improve health outcomes for individuals with special health care needs by:
 1. Understanding family-centered care
 2. Promoting collaboration on the health care team
 3. Improving communication
 4. Developing health care plans
 5. Maintaining personal medical records



Family-Centered Health Care

- Respect and dignity
- Information Sharing
- Participation
- Collaboration



Respect and Dignity

Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.





Information Sharing

Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.



Participation

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.





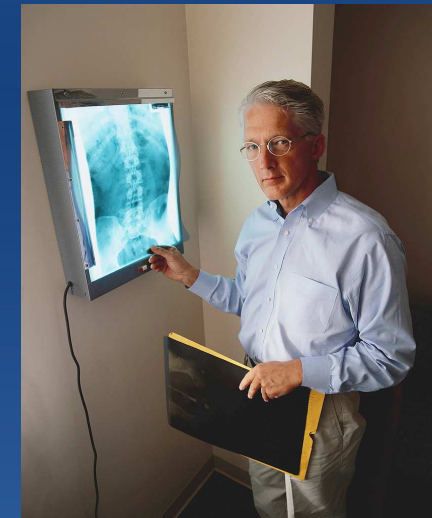
Collaboration

Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.



The Health Care Team

The health care team may include a number of health care professionals, doctors, nurses, pharmacists, therapists and always the individual with special health care needs and their family.





The Health Care Team

You have an equal voice in the treatment of yourself and your child with special health care needs because



you have expertise that no one else has!



Becoming an effective and collaborative team member

- Be well informed and prepared
- Set reasonable goals— one at a time



- Be calm and persistent
- Express your needs and opinions clearly and directly

- Ask questions if you do not understand





You WILL Disagree!

- You can disagree, but don't be disagreeable
- Avoid the “blame game”
Use “I” instead of “you”
- Be willing to **COMPROMISE!**





Goals of Good Communication

- Positive, respectful, trusting relationship with the health care team
- Satisfaction with health team
- Good health outcomes





Always Remember

- Remain realistic about what you can expect of your doctors, one doctor cannot solve all the problems or answer all of your questions
- As part of the health care team you have a responsibility for good communication, follow up, and keeping good records
- Doctors are human and, like you, may at times be frustrated with a lack of answers about what is happening.



Before Your Doctor's Appointment

- Get a long enough appointment
- Keep a journal documenting your health related concerns, physical and mental
- Write down all of the medications currently taken
- Write down your questions:
 - **Why do I get dizzy after taking this medication?**
 - **Why doesn't my son sleep after taking his ADHD medication?**
 - **Is it normal to gain weight on this medication?**
 - **My child keeps injuring himself, is there any medication that can help?**

This may seem like a lot of work, but this is YOUR body. YOU have to be in control of your health.

- Prepare your child for the doctor's visit: Who, what, when, where, and why!



During the Doctor's Appointment

- Listen and take notes
- Repeat back to the doctor YOUR understanding of what has been discussed
- Develop a written plan
- Plan for follow-up
- Ask questions:
 - Are there other doctors that need to be involved?
 - Is this doctor coordinating the care?
 - What else should be done or considered?



During the Doctor's Appointment

If the doctor does not have time to answer all your questions or needs time to look into the matter, give the doctor a written list of questions and ask that he or she call you back or set up a time to follow-up



If you anticipate a major discussion, diagnosis, or treatment plan at the appointment, consider taking a trusted friend or family member with you



Developing a Health Care Plan

- Develop a plan based on your child's need
- Decide with the doctor how often the plan needs to be updated
- Use this as a communication tool with other doctors and health care team members
- Bring the plan with you to each appointment and keep a copy on the computer, if you can





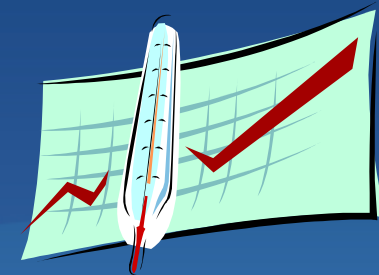
What goes into a plan?

- Describe current status or changes
- Doctors involved/last appointment
- Recommendations from last appointment/next appointment needed/ referral needed?
 - Current medications
- Tests needed or follow-up on recent tests
 - Other issues
- Follow-up required/date of next up-date



Medical Records: Why Have Them?

- Review for accuracy
- Gain more knowledge about diagnosis
- Resource for questions about diagnosis
- Filing appeals for public benefits
- Information in an emergency
- You may have the only complete set of records due to multiple providers
- Communication with specialists
- Historical record of changes/status/improvements





Your Rights

- You have a right to a copy of your and your child's medical records
- Submit a written request to provider or hospital
- You may have to pay a fee for records
- Exception to fee: If you are requesting to review "current medical care"



Keeping a paper trail

If it's not in writing, it didn't happen!



Keep Your Own Notes

- Keep a written call log for anyone you speak to on the phone, this can provide documentation about your concerns/ actions
 - -Date and time of call, name and title of person you spoke with, phone number, reason for call, information received, outcome/follow-up
- Record notes about changes or concerns about your child's/your condition
 - Temperatures, eating and sleeping issues, medication reactions, changes in behavior



Have a Medical Home

- A medical home is not a building, house, or hospital, but a better, family-centered way to provide care for children with special health care needs and disabilities.
- A pediatrician or family practice physician coordinates care to make sure your child receives all the medical and non-medical services needed.



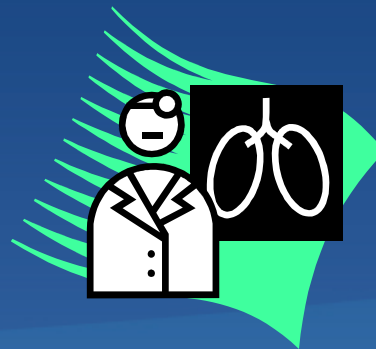
What a Medical Home Should Do

- Should be helpful in coordinating and communicating when multiple doctors or issues are involved, (hospitalizations, emergency care, health plans)
- Should address other health issues and look at the needs of you as a whole person
- Should know you well and have a trusting relationship with you



How Does a Medical Home Work?

In a medical home, information and concerns are shared by everyone caring for your child. Needs are addressed in a coordinated way, with a primary care doctor and their clinical staff serving as a coordinator of your medical home team. A written care plan is shared with your family and all of your child's health care providers.





Roles

The primary care physician and other health care providers:

- Know the child's health history
- Listen to the parents' and child's concerns and needs
- Work in partnership with families to ensure that the medical and non-medical needs of the child and family are met
- Create a trusting, collaborative relationship with the family
- Treat the child with compassion and understanding
- Develop a care plan with the family for their child when needed
- Share impartial and complete information on an ongoing basis



Additional Roles

The parents and child:

- Are comfortable sharing concerns and questions with the child's primary care physician and other health care providers
- Routinely communicate their child's needs and family priorities to the primary care physician, who promotes communication between the family and other health care providers when needed
- Feel comfortable asking for things to be explained differently when they don't understand



A medical home physician ensures care that is:

- *Accessible*
- *Family-Centered*
- *Continuous*
- *Comprehensive*
- *Coordinated*
- *Compassionate*
- *Culturally effective*




Benefits



- More organized care
- More efficient communication – families don't have to repeat information to multiple caregivers
- Support from a team of caregivers
- Exams scheduled in a coordinated, efficient way without duplicated services
- Improved health care for your child





Teach Children to be Self-Advocates

- Start early
- Give them choice when there is choice
- Encourage them to answer and ask questions, ask doctor to make time for this
- Teach them about their diagnosis
- For young children it may help to have a doll or action figure





Teach Children to be Self-Advocates

- Gradually teach them and give them responsibility for health care procedures and routines
- Making doctor appointments, ordering medications/supplies
- For older children/teenagers, ask doctor for different ways to communicate directly with them such as e-mail





Communicate with School

- Have a school health plan
- Communicate with person in charge of student health (school nurse)
- Ask the doctor to help with school issues
 - Doctors can explain diagnosis, health needs and accommodations in school
 - Doctors can make professional recommendations
 - Doctors can and should participate in IEP/504 meetings



Keep in Mind

You can always change doctors
if it just isn't working





Resources

- National Center of Medical Home Implementation
www.medicalhomeinfo.org
- Center for Medical Home Improvement
www.medicalhomeimprovement.org
- Pacer Center
www.pacer.org



Questions?

Contact AJE at one of our locations:

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**Check out our website!
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