

Six Tips for Helping Parents Advocate for Their Child's Care

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When parents learn their child has a disability or special health care need, they may not realize that they have stepped into a new role as their child's most important advocate in the health care system. By improving their advocacy skills, parents can learn to speak on their child's behalf more effectively and will be better able to secure needed services. Because pediatricians or primary care physicians are often the first people to discuss a child's disability with parents, they are in a unique position to offer advice that will help parents understand this new role.

A physician's advice about how to advocate can help parents as they seek to create a healthy life for their child. It will also help physicians develop a trusting, collaborative relationship with the family and model for parents a family-centered view of health care.

How You Can Help

As a physician, you can first help parents by letting them know that their role in their child's care is vital. They are the expert on their child and will need to advocate on their child's behalf in the health care system. They will be the one constant presence in their child's life as physicians, nurses, therapists, and others come and go. You can assist parents by sharing the following tips for effective advocacy. Physicians can help parents:

1. Understand the Disability

- Explain to parents that understanding all they can know about their child's specific diagnosis is the first step to becoming an effective advocate and providing the best care for their child.
- Recommend specific books, articles, or Web sites on the disability or special health care need.
- Suggest to parents that joining support groups or specific organizations focused on the disability or special health care need may be helpful.

The more families understand their child's specific diagnosis, the more they will be able to know if the services provided are appropriate to meet their child's needs. The knowledge they gather will also allow families to ask educated, informed questions.

2. Know the Key Players

- Let parents know key people at the medical facility who can assist them, such as a patient representative or billing coordinator.
- Provide a list of organizations that can offer parents more information about advocating for their child, including:
 - o The local Parent Training and Information Centers (PTIs) or Community Parent Resource Centers (CPRCs), which can be found at www.parentcenternetwork.org or by contacting the National Parent Technical Assistance Center at PACER Center, www.PACER.org.
 - o The state Family-to-Family Health Information Center, which can be found at www.familyvoices.org.

3. Know Rights and Responsibilities

- Tell parents about the designated staff member who can help them understand their rights under their health care plan.
- Let parents know that they are an important part of the health care team, participating in decision making about their child's care. This means that they have responsibilities for communicating with you, keeping records, and following up.

4. Become Well Organized

It is easier to advocate for good health care and communicate well with a doctor if parents are prepared and organized. As a physician, you can share with parents the steps they can take before an appointment to assure a productive visit. Before an appointment, parents can:

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- *Keep a journal.* Tell parents that it is helpful if they write down observations of behavior, reactions to medications, sleep patterns, eating habits, or anything else that may be valuable information for a physician.
- *Keep medical records.* Inform parents that they have the right to copies of their child's medical records. Encourage them to keep records of tests, procedures, and their results.
- *Write out questions.* Remind parents that they should not hesitate to ask questions and should not be embarrassed to ask for clarification when they don't understand something the physician says.
- *Prepare the child.* Tell parents that an appointment will usually go more smoothly if they tell their child what to expect, who they will be seeing and why, and what tests may be done. Remind them to bring the child's comfort items along on the appointment.

5. Use Clear and Effective Communication

As a physician, you can help parents learn effective skills by:

- Providing an atmosphere conducive to effective communication including a willingness to talk with them about any concern that may arise after the appointment.
- Encouraging parents to ask questions if they are unfamiliar with a term or do not understand something.
- Modeling good communication by rephrasing for clarification what the parent tells you.

6. Know How to Resolve Disagreements

Within the health care system, it is important for parents to understand their insurance coverage and any appeals process if they need to resolve a disagreement.

- Encourage parents to speak with a staff member designated to help with insurance coverage if they have coverage questions, and to call their health plan's customer service line.
- Let parents know that they can contact their child's primary physician if they need help with referrals or appeals, and that they should always involve their child's pediatrician in the coordination of care. This will ensure smooth delivery of services and good communication among all providers.
- Remind families that requests, referrals, or orders for services should come from a physician. Requests from a therapist or licensed psychologist may not be accepted by health plans.
- Let parents know that if they ever appeal a decision on health insurance coverage, they are welcome to contact your office to see if you can provide support.

Conclusion

Helping families strengthen their advocacy skills benefits the child's care now and in the future. Families who are acknowledged as a vital member of a health care team and develop these skills can better help their child secure needed supports and services. Pediatricians and primary care physicians are key players who can lay a foundation for how parents approach their child's care and can empower parents in their vital role as advocates for their child.

About the Authors:

PACER Center is a national parent training and information center. PACER expands opportunities and enhances the quality of life of children and young adults with any disability and their families. PACER Center is located in Minneapolis, MN. For more information, call 952/838-9000 or visit PACER.org.

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