

# Physicians: What Parents Want You to Know About Their Child With Special Needs

## The Parent's Point of View

### I Like You When You:

- ◆ Recognize my denial, anger, and healthy and natural response to grief.
- ◆ Accept that my child's health care needs are only a part of my family's priorities and that sometimes my family's needs and concerns may take precedence.
- ◆ Value that I'm the expert on my child.
- ◆ Acknowledge that I am a competent partner in health care.

### What I Need From You:

- ◆ Help me find the information I need to understand my child's condition. My child's condition is not temporary. I'll be learning about it for a lifetime.
- ◆ Do not withhold or omit any information concerning the severity or extent of my child's condition. Also, do not hesitate to use medical terms when necessary.
- ◆ Help me to understand the range of possibilities. Tell me the worst and best possible prognosis.
- ◆ Acknowledge my sense of urgency by responding quickly to requests for medical information, referrals, etc, so that appropriate services can begin or continue.



- ◆ Remind me of my child's strengths from time to time.
- ◆ Collaborate with other professionals providing care for my child.

If it sometimes seems I expect you to be my social worker, psychiatrist, and omnipotent seer of the future... well I do!

### **P.S. Thanks for being my competent partner in health care!**

The American Academy of Pediatrics (AAP) believes that all infants, children, adolescents, and young adults should have access to a "medical home" that provides comprehensive, coordinated, and family-centered health care.

This goal presents unique challenges for pediatricians offering primary health care to children with special needs within this changing health delivery system. To meet those challenges, the Medical Home Program for Children With Special Needs identifies

and promotes model strategies, training, and technical assistance. By supporting physicians, and other health care professionals, the Medical Home Program for Children With Special Needs seeks to provide better health care for all children.

For more information on how the Medical Home Program for Children With Special Needs can be a resource for you, or if you would like to be added to the mailing list, contact Liz Osterhus, AAP Department of Community Pediatrics, 800/433-9016, ext 7621.

*Parent-professional collaboration is an essential component in the provision of medical homes for children with special needs. This document was brought to you by the American Academy of Pediatrics, Medical Home Program for Children With Special Needs with funding provided by the federal Maternal and Child Health Bureau.*

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