

Parents as Partners in the Medical Home, Part 2

Choosing a Pediatrician



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Not all physicians are prepared to treat all children who have complex chronic physical and health problems. Some healthcare providers are reluctant to work with these children because they lack knowledge and experience. Others are concerned about getting reimbursed for the additional time involved in caring for children with these special needs. Still others question the value of various tests and treatments. As a result, many families have to search for doctors who are ready, willing, and able to care for their children.

Finding a qualified, responsive physician is just one part of the families' quest for medical services. Families also have extensive interactions with medical staff. Receptionists, nurses, care coordinators, and x-ray technicians fill many functions, including answering the phone, communicating information to the physician, administering lab tests, assisting during the examination, making referrals, and negotiating with managed-care personnel. As a result, the skillfulness and attitudes of the medical staff also have a significant

impact on the family's level of stress and sense of satisfaction. Selecting a pediatrician should include consideration of the qualities of the medical support staff.

What qualities are needed by pediatricians and staff serving families and children with special healthcare needs?

A team of parents and professionals collaborated in order to systematically define the qualities that make pediatricians and their staff effective in working with families and children with serious, complex physical and health problems. The team included parents participating in the Parents as Partners in the Medical Home Project*. The Medical Home is a recently developed model of pediatric healthcare (as defined by the American Academic of Pediatrics and the Maternal Child Health Bureau) in which providers ensure that children and their families have medical and non-medical services that are accessible, continuous, comprehensive, and coordinated in a compassionate and culturally competent manner. The Medical Home

Correction: In the previous issues the authors Tanis Bryan, PhD, and Karen Burstein, PhD, were incorrectly identified as being with the University of Arizona. Both authors are faculty members at the Arizona State University, Tempe. We sincerely apologize for the error and any inconvenience this may have caused.

concept emphasizes that families play an active role on the medical team, and that they be recognized as partners in caring for their children.

The families who participated on the team are all residents of Arizona and were representative of the state's diverse population. Families included those of African-American, Anglo, Latino, and Native American backgrounds. They have children ranging from 17 months to 24 years with Down syndrome, reactive airway disease, autism, metabolic disorders, myelomeningocele, cerebral palsy, epilepsy, congenital heart disease, and developmental delays. Most of the children have multiple conditions. The professional members of the team included pediatrician David Hirsch, MD, and Clinical Care Coordinator Diana Frieberg, BSN, both of Phoenix Pediatrics, Ltd.; special education faculty from Arizona State University (and authors of this article) Tanis Bryan, PhD, and Karen Burstein, PhD; and a parent/professional Judie Walker, of Raising Special Kids. Raising Special Kids is a statewide grassroots organization of parents of children with disabilities that provides parent training, support services, and information dissemination statewide.

**Defining the qualities that
make pediatricians and staff
effective for children with
special healthcare needs**

The team met monthly in its study of healthcare providers for children with special healthcare needs. They reviewed related research, most of which focused on physicians' communication styles during medical interviews. Although communication skills are clearly a critical component of the physician's effectiveness, team discussions led to a much broader view of necessary physician characteristics. The team extended the discussion to include quality indicators of the medical staff (e.g., cheerfully greets caregiver and child by name) and the medical practice (e.g., phone system allows access to medical staff within reasonable time). The factors that parents identified as critical in physicians and staff serving children with special healthcare needs were assembled into the Survey *Quality Indicators of an*

**The Survey
Quality Indicators
of an Effective
Pediatrician for
Children with
Special Healthcare
Needs can be
a useful tool
for parents
and caregivers
as well as
physicians
and staff.**

Effective Pediatrician for Children with Special Healthcare Needs (see Table 1 on the following page).

Pediatricians who are perceived by families as effective with children with special

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healthcare needs have a special set of attitudes, knowledge, interpersonal style, and communication skills. Parents define a positive attitude as showing empathy to the child and family and giving the family realistic reasons to be hopeful and optimistic. Knowledge is defined by expertise in diagnosis and current treatments. Interpersonal style refers to the time the physician takes with the family, not being rushed, and providing open-minded feedback to the child and families. Effective communication skills are defined as: being a good listener, listening to all symptoms before making a diagnosis, using familiar terminology or carefully defining new terms, and speaking to the child even if the child cannot respond verbally.

The effective physician also has a support staff that has been well trained to work with families and children with special healthcare needs. The support staff's style in working with the child and family should reflect the attitudes and values of the physician. Hence, greeting the family and the child, explaining the procedures that are to take place, and validating the patient's concerns about painful procedures should be a basic part of the examination. Finally, parents indicate that how the medical practice is organized is very important. Meeting family needs requires that the practice provide features such as: reasonable phone access to staff; consistent procedures in each examination; and streamlining procedures for paying the bill. The staff contribute significantly to helping the child and family through the many medical encounters that are a mainstay of the child and family's life.

The Survey (Table 1) can be a useful tool for parents and caregivers as well as physicians and staff. It provides a set of standards that parents and caretakers can use to evaluate the quality of care their children are receiving. Physicians

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can use it to evaluate the quality of care they are providing to children with special healthcare needs. Physicians also can use the Survey as a guideline for staff training and office management.

Acknowledgement

We gratefully acknowledge the contributions of parents in the Improving Managed Care for Children with Chronic Health Care Needs Project. The study would not have been possible without the participation of Sharon Atwood, Elli Bogden, Lisa Carlson, Sherry Charlott, Janet Churchward, Brad Geeck, John Gooch, Velma Leftwich, Jackie Marchosky, Angela Moberg, Mae Moore, Sandra Partker, Aura Rubin, Bonnie Rubio, Leah Vincent, Darlene Watkins, Julie Webb, and Martha Young.

The *Improving Managed Care for Children with Chronic Health Care Needs by Including Parents as Participating Partners in the Medical Home Project* is supported by grant #041517 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Tanis Bryan, PhD, and Karen Burstein, PhD, both special education faculty at Arizona State University, Tempe, are Co-principal investigators for the Medical Home Project Team.

Dr. Bryan brings extensive knowledge and experience in conducting community-based investigations to the team.

As a parent of a child with special healthcare needs and former CEO of a children's rehabilitation facility, Dr. Burstein brings expertise on the problems of families and children as well as research design to the team.

QUALITY INDICATORS OF AN EFFECTIVE PEDIATRICIAN FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS

This survey is a tool to help evaluate the quality of care received from your child's healthcare provider. Parents/Caregivers of children with special healthcare needs identified these traits as important to quality of care. Please respond to each item by indicating whether your child's healthcare provider exhibits these behaviors:

1= ALMOST ALWAYS 2= SOMETIMES 3= HARDLY EVER 4= ALMOST NEVER.

Please feel free to add your comments, explanations, or any additional information that you believe will help us improve the quality of care for children. Thank you in advance for completing this survey.

Child's Age _____ Child's Gender _____ Name of Healthcare Provider _____

Type of Services Provided _____

Type of Visit: Routine Emergency Follow-up

My child's physician:

ATTITUDE

Responds to child's needs first 1 2 3 4
Shows empathy to child and family 1 2 3 4
Is nonjudgmental 1 2 3 4
Gives families realistic reasons to be hopeful and optimistic 1 2 3 4
Involves family in finding solutions 1 2 3 4
Invites and responds positively to family's ideas and suggestions 1 2 3 4

COMMUNICATION SKILLS

Is a good listener 1 2 3 4
Has direct eye contact with child and Parent/Caregiver 1 2 3 4
Asks questions to refresh Parent/Caregiver's memory 1 2 3 4
Encourages Parent/Caregiver and child to ask questions 1 2 3 4
Responds to family's communication style 1 2 3 4
Uses familiar terminology or carefully defines new terms 1 2 3 4
Speaks to the child even if child cannot respond verbally 1 2 3 4
Touches child when necessary 1 2 3 4
Has a gentle touch 1 2 3 4
Explains treatment in detail 1 2 3 4
Checks to make sure Parent/Caregiver understands instructions 1 2 3 4
Makes statements that are sensitive and appropriate 1 2 3 4

INTERPERSONAL STYLE

Takes time and does not seem rushed 1 2 3 4
Provides encouragement to child and Parent/Caregiver 1 2 3 4
Provides open minded feedback to child and Parent/Caregiver 1 2 3 4
Collaborates with child and Parent/Caregiver in seeking solutions 1 2 3 4
Is not defensive 1 2 3 4
Shows patience 1 2 3 4
Is respectful of Parent/Caregiver experience and knowledge of the child 1 2 3 4
Trusts the Parent/Caregiver 1 2 3 4
Is compassionate and kind hearted 1 2 3 4
Suggests ways that Parent/Caregiver can improve in taking care of child 1 2 3 4
When appropriate, assures Parent/Caregiver that he/she is doing a good job in caring for the child 1 2 3 4
Provides extra TLC through giving such things as "special" bandages, hard candy, stickers 1 2 3 4
Takes Parent/Caregiver concerns seriously 1 2 3 4
Shows personal involvement and interest in the family 1 2 3 4

KNOWLEDGEABLE

Listens to all symptoms before making a diagnosis 1 2 3 4
Is knowledgeable about child's condition, past and current status 1 2 3 4
Is very knowledgeable about diagnoses and current treatments 1 2 3 4
Is up to date on current medications 1 2 3 4
Gives options for solving problems 1 2 3 4
Volunteers information about agencies that provide additional services 1 2 3 4
Knows how to access other agencies that provide services 1 2 3 4
Follows through on care 1 2 3 4
Follows up on outcomes 1 2 3 4
Stays current with recent research 1 2 3 4

MEDICAL SUPPORT STAFF

Cheerfully greets Parent/Caregiver and child by name 1 2 3 4
Informs Parent/Caregiver about actual wait time 1 2 3 4
Introduces self and explains role 1 2 3 4
Talks to child even if child is not verbal 1 2 3 4
Explains the procedures 1 2 3 4
Explains what is expected of the child during the examinations or procedure 1 2 3 4
Talks the child through the procedure 1 2 3 4
Takes direction from the child 1 2 3 4
Validates the child's feelings (e.g., fear, pain) 1 2 3 4
Reviews chart and medications 1 2 3 4
Uses appropriate prompts and reinforcers 1 2 3 4
Is comfortable touching the child 1 2 3 4
Does thorough and accurate assessment of the child 1 2 3 4
Says good-bye 1 2 3 4

MEDICAL PRACTICE

Staff has low turn-over 1 2 3 4
Phone system allows access to medical staff in reasonable time 1 2 3 4
Staff uses consistent procedures for handling children (e.g. weighing, disrobing) 1 2 3 4
Staff notifies Caregiver/ Parent in advance about billing problems 1 2 3 4
Staff writes co-pays on chart or super bill 1 2 3 4