"Every Child Deserves A Medical Home"

What is a Medical Home?

A Medical Home is not a building, house, or hospital, but rather an integrated and trusted partnership to provide health care services in a high quality, cost effective manner.

Pediatric health care professionals and parents act as partners in a Medical Home to identify and access all medical and non-medical services needed to help children and their families achieve maximum potential.

Medical Home promotes community-based primary care that is accessible, comprehensive, continuous, and coordinated, delivered in family-centered, compassionate, and culturally effective ways.

Medical Home Works! aims to increase capacity in developing community-based partnerships between families, physicians, and community agencies to address the needs of all children, particularly children with special needs. This Medical Home Family Stories video series provides brief family stories to stimulate discussion, learning, and implementation of Medical Home strategies that work.

DVD Video: Bryan's Story (15 min.)
DVD ROM Companion Materials:
- **Family Inserts**
- **AAP Resources**
- **DVD Evaluation**
- **Key Internet Links**

Bryan's Story Production Team Sends Special Thanks to:
Rosalinda & Larry Alfaro, Leo Pascua, Cora Johnson, and Susan Miyamoto

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Related Resources:
- www.medicalhomeinfo.com-Website for the National Center of Medical Home Initiatives for Children with Special Needs
- www.aap.org-Website for American Academy of Pediatrics, see Department of Community Pediatrics
- www.mchb.gov-Website for U.S. Maternal and Child Health Bureau, Division for Children with Special Health Care Needs

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Video Guide
Medical Home Works!
presents
Medical Home Family Stories

Bryan's Story

Spotlighting community-based, family-centered, comprehensive, coordinated, collaborative care

"Every Child Deserves A Medical Home"

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DVD Video & DVD ROM

Bryan Alfaro

Bryan, eight years old, lives in rural Oahu, Hawaii, with his parents who immigrated from the Philippines and two younger sisters. Bryan was slow to start walking and demonstrated emotional outbursts at home and at his Head Start pre-school when he "did not get his way." Bryan's family identified him as "lazy" because he wanted to be carried all the time. Head Start staff considered him to be "uncooperative" when he refused to join in activities and tantrumed often. Medical Home Partners persistently worked together to identify Muscular Dystrophy when Bryan was three and a half.

Principal Medical Home Partners

- Parents: Rosalinda and Larry Alfaro
- Primary Care Physician: Leo Pascua, MD, Pediatrician
- Head Start Teacher: Susan Miyamoto
- Head Start Nurse: Cora Johnson, RN
- Medical Specialists: Neurologist, Geneticist

Dr's Notes on Bryan

- Late walker
- Increasing lack of coordination when compared to peers at age 3.5 years
- Large calves, dense muscles
- Duchenne Muscular Dystrophy

Learning Objective

- Understand the roles of Medical Home partners
- Analyze strategies for early identification and breaking diagnostic news

Learning Points Suggested by Physicians

- **Physicians are not the only partner in a Medical Home.** As one physician put it, "Doctors often have a professional conceit that may undermine their process of learning and implementing effective strategies for Medical Homes." Successful Medical Homes incorporate families, other professionals such as teachers, and community-based agency staff as partners to comprehensively respond to a child's health care needs.

- **Medical tests are not the only diagnostic resources.** Physicians need to utilize all available diagnostic resources. Rather than using only medical diagnostics (in Bryan's case, lab reports, imaging, etc.), a physician can gain increased understanding of a child's development by also including information that may not have a medical source, e.g., the family, early education staff. Constraints of office practice (limited clinical time commonly spent with a child) mean physicians need to ask, "How do I elicit information from other Medical Home partners to provide a more complete picture of this child's situation?"

- **Optimism vs. skepticism.** Physicians must consider applying both approaches when making diagnoses. Parents and health care providers may give differing meanings to behaviors in children that do not match "the norm." Some may prefer a cautious approach to assess how a child develops over time; others may focus on a perceived "problem" at the earliest possible time. It is important to take every clue, watch and listen carefully to the people who know the child best.

- **Breaking diagnostic news—using family-centered and compassionate strategies.** A physician breaks diagnostic news by furnishing the family with thorough information about their child's medical condition and treatments, the medical system itself, as well as community resources and services. Affirming the family as partner is key in establishing open communication and trust. Physicians and other health professionals can build even greater trust and credibility by considering the timing, the intensity and urgency of information provided while assessing when the family is ready for the next phase of new information.

Learning Points Suggested by Families

- **Parents are primary partners in their child's Medical Home.** Medical Homes for all children, especially children with special health care needs, involve a partnership between physician, family, and community providers. As primary care givers, families are key in providing critical information, making decisions, contributing to care-coordination, and implementing links to important community resources.

- **Locate an advocate who will listen and act.** Families often have a deep "gut feeling" that something is "wrong" with their child even before a problem is diagnosed. At times, cultures of families may prevent parents from speaking openly with their child's physician (for example, seeming to contradict the physician, lack of a common language, not being able to fully describe exactly what is wrong, not persisting beyond the first mention of their concern). Parents can greatly benefit by locating someone who will listen to their beliefs that something is wrong (perhaps a physician or staff from community-based programs) and who can act as an advocate for the child and family to achieve early identification.

- **Innovative communications can promote effective identification.** Bryan's Head Start teachers and nurse felt pressed to communicate their concerns about Bryan's development to the physician. Head Start staff recorded several hours of video so the physician could observe Bryan's behavior and physical skill level that had not been apparent in brief pediatric office visits.

- **Incorporating health is essential for early education.** When children access early education programs that have an integrated health component, a significant result may be early identification concerns regarding a child's physical, emotional, and behavioral development. Possible outcomes: avoiding increasing intensification of an identified problem; possibly reducing an identified problem; limiting the frustration, pain, and expense of acute care as much as possible; and, developing vibrant community-based services that support all children.