

A NEW WAY... A BETTER WAY

**BUILDING MEDICAL HOME PARTNERSHIPS*
FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

TIPS FOR FAMILIES



Department of Health and Mental Hygiene



Office for Genetics and
Children with Special Health Care Needs

- * When families and their doctors work together to make comprehensive care in the community a reality, this partnership is called a Medical Home.

WHAT IS A MEDICAL HOME?



The American Academy of Pediatrics, the American Academy of Family Physicians and the national Maternal & Child Health Bureau are promoting Medical Home partnerships between families caring for children and youth with special health care needs and the physicians they trust. In a Medical Home, families and physicians work together to identify and access all the medical and non-medical services needed to help children and their families reach their greatest potential.

- Medical Home is not a building, house or hospital. It is a way of providing high quality health care services in a cost-effective manner.
- Medical Home is as much an attitude as it is a way of providing care: families are viewed as the main caregivers and the center of strength and support for children.
- Medical Home is another way of describing the supports and services families should expect from their child's pediatrician or other primary care provider's office.

A doctor who works to provide a Medical Home is offering far more than routine or crisis medical care. He or she will work with you to build a home base for your child with special needs.

A NEW WAY... A BETTER WAY

Families caring for children and youth with special health care needs can look to their child's primary care doctor and office staff for help in planning their child's care and finding the services they need at home and in the community. When a child has many health care needs, the family may require help finding resources, setting priorities and coordinating care with a variety of providers.

An ongoing relationship with a pediatrician, family physician or pediatric nurse practitioner can provide a home base to look at the needs of the whole child and family, and a place to:

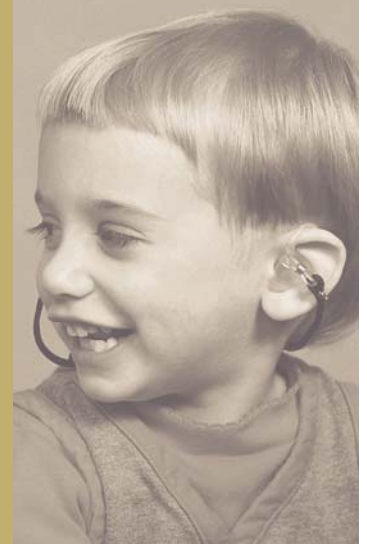
- Make sure that your child has the proper immunizations
- Talk about normal child development concerns
- Get help with school-related issues
- Find out about resources in the community for your child
- Have the "big picture" needs of your child and family considered

HOW DO I KNOW IF MY CHILD HAS A "SPECIAL HEALTH CARE NEED"?

Children and youth with special health care needs are those from birth to 21 years old who:

- have a chronic physical, developmental, behavioral, or emotional condition expected to last 12 months or more, and
- need health and related services more than most children.

This includes children and youth with chronic medical conditions such as diabetes, sickle cell anemia, cystic fibrosis, and heart disease; developmental disabilities such as mental retardation, hearing and vision impairments, and autism spectrum disorders; emotional or behavioral conditions such as depression or ADHD; and physical disabilities such as cerebral palsy, spina bifida, and muscular dystrophy.



WHAT SHOULD I EXPECT FROM MY CHILD'S MEDICAL HOME?

Your child's pediatrician or family physician may not have all of the following pieces of Medical Home in their practice, but it will help to know what to ask for and what you can work on together. You can use this list when choosing a new physician for your child, or as a way to start a conversation with your child's doctor about Medical Home.

Your child's primary care doctor and their office is accessible.

- Available after hours, on weekends and holidays
- Accepts your child's health insurance
- Office and equipment physically accessible to your child

Staff within your child's primary care office know you and help you.

- Know you and your child when you call
- Recognize and accommodate your child's special needs
- Respond to requests for letters, medical records, and other paperwork that you may need for your child's insurance or for other programs and services
- Provide written materials in a language you understand

Your child's primary care doctor respects you and listens to your thoughts and concerns about your child.

- Asks you to share your knowledge about your child
- Seeks your opinion when decisions are needed
- Talks to you about how your child's condition affects your family (other children in the family, child care, expenses, work, sleep)
- Acknowledges and respects your family's cultural values and religious beliefs
- Provides interpreter services if needed

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My child's doctor is already doing many things on the list but others in the practice do not. Is there a way to make this a more routine approach used by all the doctors in the office?

Ask your child's doctor if some of the family-centered things she does could become more general office practice. Suggest that the office organize a meeting of parents, staff and providers to talk about how to improve services for families like yours.

WHAT SHOULD I EXPECT FROM MY CHILD'S MEDICAL HOME?

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Your child's primary care doctor and office staff work with you to plan your child's care.

- Help you set short-term (3-6 months) and long-term (the next year) goals for your child
- Give you important information, such as recommendations or new treatments, in writing
- Work with you to create and update a written plan of care for your child's medical and non-medical needs
- Review your child's medical records with you when needed
- Help you consider all of the possible treatments for your child's condition, including new and alternative therapies

Your child's primary care doctor and office staff support you as a caregiver.

- Help you connect with family support organizations and other parents in your community
- Provide information on community resources like respite and recreational activities
- Find and share new information, research or materials that are helpful in caring for your child
- Help you to advocate on behalf of your child
- Plan for adult health care services (if appropriate for your child's age)

Your child's primary care doctor and office staff help you to coordinate your child's care.

- Follow up with difficult referrals
- Help you to find needed services such as transportation, durable medical equipment, home care, and ways to pay for them
- Explain your child's needs to other health professionals
- Reach out to your child's school or day care providers to help them understand your child's medical condition
- Encourage and support frequent communication between all persons involved in your child's care (with your consent)
- Organize and attend team meetings about your child's plan of care that include you and other providers

Our pediatrician doesn't do many of the things listed, but we like the office. I don't want to switch from this caring doctor, but I would like to get more services and support.

Don't give up a good and trusting relationship with your family doctor – it is very valuable. Let your doctor know that you appreciate the care he provides to your child and family, and talk about how you could work together to make it even better. Try sharing some of the ideas and resources listed in this brochure.

RESOURCES FOR BUILDING MEDICAL HOME PARTNERSHIPS IN MARYLAND

Learn about Medical Home activities across the country and find tools for families:

American Academy of Pediatrics
National Center of Medical Home Initiatives
for Children with Special Needs
141 Northwest Point Blvd
Elk Grove Village, IL 60007
phone: 847-434-4000
email: medical_home@aap.org
website: www.medicalhomeinfo.org

Join family leaders and providers working to promote Medical Home in Maryland:

Maryland Department of Health and Mental Hygiene
Office for Genetics and Children with
Special Health Care Needs
201 West Preston Street
Baltimore, MD 21201
phone: 800-638-8864
website: www.fha.state.md.us/genetics

Connect with other families for information and support:

The Parents' Place of Maryland (Maryland Family Voices)
801 Cromwell Park Drive, Suite 103
Glen Burnie, MD 21061
phone: 800-394-5694
e-mail: info@ppmd.org
website: www.ppmd.org

Learn about Medical Home activities and resources throughout the state:

The Resource Network
Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
phone: 800-390-3372
e-mail: resourcefinder@kennedykrieger.org
website: www.resourcefinder.kennedykrieger.org

ASK Program (Access for Special Kids)
University of Maryland Hospital for Children
22 South Greene Street
Baltimore, MD 21201
phone: 410-328-6879

CSHCN Liaison at Children's National Medical Center
111 Michigan Avenue N.W.
Washington, DC 20010
phone: 202-476-4904

CSHCN Liaison at Johns Hopkins Children's Center
600 North Wolfe Street
Baltimore, MD 21287
phone: 410-614-8292

Regional Resource Center for Children with Special Needs
Wicomico County Free Library
122 South Division Street
Salisbury, MD 21801
phone: 410-219-2886
website: www.regionalresourcecenter.org

I would like to find a new physician who "gets it," and is interested in these ideas about Medical Home. Where do I start?

There are a growing number of doctors working to provide a Medical Home for children and youth with special health care needs in our state. Other families are often the best source of information. Try contacting a family support organization like The Parents' Place of Maryland (1-800-394-5694) and asking for recommendations from other families. You can also contact the Office for Genetics and Children with Special Health Care Needs in the Maryland Department of Health and Mental Hygiene (1-800-638-8864) for assistance with identifying practices in your area.



101 Tremont Street
Suite 812
Boston, MA 02108
www.neserve.org



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