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 on-going 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

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. Since Medical Home is a new concept, try sharing some of the ideas and resources listed in this brochure.

RESOURCES FOR BUILDING MEDICAL HOME PARTNERSHIPS IN MASSACHUSETTS

Learn more about Medical Home activities across the country:

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

Learn about the Massachusetts Care Coordination Program and other state resources:

Massachusetts Department of Public Health
Community Support Line
Division for Perinatal, Early Childhood & Special Health Needs
250 Washington Street
Boston, MA 02108
phone: 800-882-1435
website: www.state.ma.us/dph/fch/famsupport.htm

Learn about Medical Home activities and community resources in your area:

Family TIES
Federation for Children with Special Needs & Massachusetts Department of Public Health
phone: 800-905-TIES (8437)
website: www.massfamilyties.org

Join Massachusetts Family Voices to connect with other families:

Massachusetts Family Voices
Federation for Children with Special Needs
1135 Tremont Street, Suite 420
Boston, MA 02120
phone: 617-236-7210 x 210 or 800-331-0688 x 210
email: massfv@fcsn.org
website: www.massfamilyvoices.org

Join other family leaders and providers working to promote Medical Home:

Massachusetts Consortium for Children with Special Health Care Needs
New England SERVE
101 Tremont Street Suite 812
Boston, MA 02108
phone: 617-574-9493
email: info@neserve.org
website: www.neserve.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 make Medical Home a reality in our state. Other families are often the best source of information. You can post a question on the Massachusetts Family Voices listserv and ask for recommendations from other families. Learn about and join the listserv at massfamilyvoices.org. You can also contact the Massachusetts Department of Public Health (DPH), 800-882-1435 to identify a practice in your region participating in the DPH Care Coordination Program.

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

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A NEW WAY… A BETTER WAY

BUILDING MEDICAL HOME PARTNERSHIPS* FOR 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.

TIPS FOR FAMILIES

New England SERVE

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 maximum potential.

- Medical Home is not a building, house or hospital. It's an approach to providing health care services in a high-quality and cost-effective manner.
- Medical Home is as much an attitude as it is a way of delivering care: families are recognized as the principal 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.

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 prior approvals, letters of medical necessity for your child's insurance, or documentation 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 observations 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

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

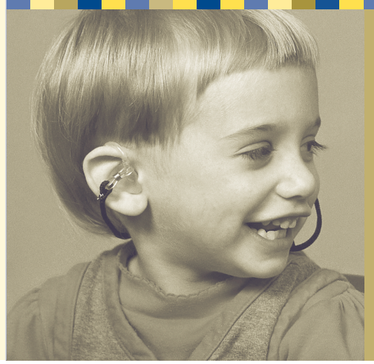
- ☐ Help you set short-term (3-6 months) and long-term (the next year) goals for your child
- ☐ Give you important information, such as recommendations or new treatments, in writing
- ☐ Work with you to create and update a written plan of care for your child's medical and non-medical needs
- ☐ Review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

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
- ☐ 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



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

Children and youth with special health care needs are recognized to be 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,
- may receive these services from various public and private agencies and providers in the areas of health, education, and social services,
- and, as a result of complex conditions and many different providers, may need help in coordinating this care.

This includes children and youth with chronic medical conditions or genetic disorders such as diabetes, sickle cell anemia, childhood cancers and heart conditions; developmental disabilities such as mental retardation, hearing and vision impairments and autism spectrum disorders; as well as emotional or behavioral health needs including ADHD and mental health conditions; and physical disabilities such as cerebral palsy, spina bifida, or muscular dystrophy.

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.