



Do You Have a Medical Home?

Making Certain Your Child and Family Receive

Coordinated, Comprehensive, Quality Health Care within a Medical Home

By Ann Donoghue Dillon and Jeanne Walker McAllister

Families have the knowledge and skills, greatly needed by health care providers, to guide the improvement of community-based medical homes. Having a medical home means patients and families experience a high quality of health care within a primary care setting in the community (the doctor's office). Access to quality, community-based, health care is particularly important to ensure optimal outcomes for children and families when special health care needs are involved. The American Academy of Pediatrics, the American Academy of Family Physicians, and the United States Maternal and Child Health

Bureau endorse and promote the concept of a medical home as a method to ensure that care is accessible, family-centered, compassionate, coordinated, comprehensive, and culturally effective.

Achieving such a level of quality requires a consistent "place" such as a primary care office with a well-prepared health care team. But a medical home is much more than just a place or a person. A strong medical home provides trusting relationships among families, children, clinicians and their staffs. A medical home team offers care which invites full family and youth participation. Families, children and youth are welcomed and

remembered by office doctors, nurses, and other staff members. In a medical home staff members learn from families and others about special needs and resources. Help is available to families for care coordination. A medical home communicates effectively with the many professionals involved, such as those at school or within community agencies. Medical homes cannot be improved without the ongoing input of the families and children whom they serve.

Some doctor's offices have developed distinct services and supports for children and youth with special health care needs (CYSHCN). As a result, the quality of their medical home is constantly improving. Other medical offices struggle to help children and families with more complex needs. Providing high quality care has become a challenge for health professionals for many reasons such as limited knowledge about rare conditions, lack of prepared staff and limited time and resources. There are also financial reasons that make investing in the improvement of care within a medical home difficult. There is usually not reimbursement (payment) for necessary additional services such as care coordination, advocacy and patient education.

In the past seven to ten years, state and national efforts have emerged to help primary care offices improve and strengthen their level of medical home activities. New Hampshire's Center for Medical Home Improvement (CMHI) has been working with many pediatric and family medicine groups in New England and nationally to help them improve the quality of their medical homes. Family participation and input has been more valuable in these efforts than any other factor. Families partner with their pediatricians or family doctors to design improvements that better meet the needs of children, youth and families.

What about You?

Do you have knowledge and skills that could be used to effect change in the medical home where your child receives care? As the parent of a child with a chronic medical condition or disability, your role as a partner has more than likely been evolving and developing since your child was first diagnosed. An opportunity awaits many parents to learn more about forming medical home partnerships with those at the practice where their children receive care. Responding to this opportunity may help strengthen the quality of care found in the practice. Some parents may perceive this as a daunting challenge among their many day-to-day pressures. But if you knew the result ahead of time - that care for your child would be better coordinated, provided with you as a valued partner, wrapped in a comprehensive and consistent package, accessed without hassles, and offered compassionately in a way that respects you, your culture and beliefs - would you be willing to accept this challenge and help make changes leading to stronger medical homes?

If your answer is yes, then the steps that follow may help you on such a journey. To begin, you will need:

- Information to educate yourself about the concept of quality care in a medical home;
- Medical partners who are interested in improving how they care for children and youth, particularly those with special needs;
- Confidence in what you have learned as the parent or guardian of a child with special health care needs, and;
- Determination to help others with your knowledge.

Ten Easy Steps for Parent Driven Medical Home Improvements

You can choose from or move sequentially through these ten steps to guide you in strengthening your child's medical home:

- 1 Learn more about the medical home
- 2 Prepare for and shape office visits
- 3 Form a care coordination partnership with a medical home
- 4 Frame key questions to ask your health care provider
- 5 Expand quality care to your community
- 6 Spread ideas about medical home to other families
- 7 Help medical home staff with small improvement projects
- 8 Join a medical home improvement team
- 9 Reach out to other parents (on behalf of the medical home team)
- 10 Evaluate continuously and design new medical home improvements

1. Learn More About the Medical Home

Parents can educate themselves about the medical home in a variety of ways. As a first step, parents need to understand what a medical home is, and what it can offer families, children and youth, practitioners, and the entire practice. Over the past ten years, there has been a widespread movement in the United States to strengthen the quality of care provided in medical homes. Numerous articles, web sites and readings are available online or in family resource centers. Readings are available to help parents understand basic medical home concepts and guide them about asking for certain kinds of care. The American Academy of Pediatrics (AAP) functions as the National

Center of Medical Home Initiatives and catalogs medical home efforts across the country. Its website (<http://www.medical-homeinf.org>) is rich with articles, and offers tools and data about children and youth with special health care needs. You can find the medical home leaders and activities in your state on this site. New Hampshire's Center for Medical Home Improvement (CMHI) also has a website <http://www.medicalhomeimprovement.org> which includes practice and family quality measurement tools and a quality improvement kit which demonstrates how to "build" or improve a medical home. CMHI's site includes descriptions of key outcomes that are the result of families, doctors and office staff coming together in partnerships to design medical home improvements. The site also includes the guide Parent Partners: Creative Forces on Medical Home Improvement Teams. New Hampshire and many other states have on-going projects with teams of people who sponsor workshops or seminars on medical home improvement. Family members associated with these projects may be willing to spend time chatting about their endeavors to other interested parents. Most states have an organization called Family Voices (familyvoices.org) whose primary objective is to act as a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. This can be a good resource for you. You can tap into all of these resources to help you gain knowledge and expertise to guide your efforts.

2. Prepare for and Shape the Office Visit

There are concrete ways that you can prepare for an office visit and improve the care

continued on page 24

continued from page 23

you receive. When you set up an appointment you can inform the receptionist about your child's special needs. You can ask for the kinds of supports that you have learned make visits go well (e.g. a quiet room, an early visit time slot, or no visible needles). You can also request a longer visit if you believe this will help. Bring with you (or send ahead of time) any pertinent information that you would like your child's doctor to have, including any health history, records, consultation summaries, or school requirements and concerns. Consider identifying your top three "most important issues" for the day's visit, and ask for help planning around these concerns. You will want enough time to offer insight into your child's condition and needs. Know that an additional visit may be needed for staff to provide time to offer this assistance and completely address your concerns. This may also be a learning process for the doctors and their staff so try to go one step at a time. Understand that their progress in these changes may be slow as they attempt to make changes while running a busy practice.

3. Form a Care Coordination Partnership

If your initial steps into the medical home arena succeed, next you might take steps to ensure more coordinated care for your child. Part of the quality improvement work of a medical home is to be able to gather information and offer care coordination with and for you on behalf of your child. Have you met with the physician and the office's care coordinator (if there is one) for a care coordination visit? Such a visit can give you knowledge and reassurance that there is someone at the office who has time to sit with you, to hear your concerns, and to help you come up with solutions or strategies to address your needs. Your doctor's team or care coordinator should have knowledge of community resources that can be helpful. The practice may be working to offer more care coordination support and to develop

Our pediatric practice decided to work on improving care within their medical home about seven years ago. Before that, we felt we were part of a wonderful practice with an open climate, respectful staff offering good care. But now, things are even better. There is a wonderful and family-centered collaboration in place to plan and implement health care improvements. Care is better for all patients and families, and clinicians and staff are more satisfied providing care. Parents play an active role identifying needs and bringing about change. As a result, children and families are remembered by office staff, visits are planned for, and the support and help of a care coordinator is available. Families help to complete and use tools designed to improve communication, such as a journal to record the events of each visit. There are medical summaries, or care plans, in place that includes all vital information about our children. Care plans help tremendously when we are away or when we need to access emergency care. Communication between the pediatrician or family physician, and subspecialists, educators, and other community-base professionals is enhanced by planned outreach activities.

What we had before was good, but what we have now is better and, I think, the best is yet to come!

—Ann Dillon – Parent of a child with special health care needs

their practice-based care coordination expertise. Comprehensive care planning is a tangible improvement medical homes have found to be very beneficial for families and staff. Families and their children benefit greatly from an up to date "medical portfolio" which includes a medical summary, an action plan, and if necessary, an emergency plan. Families can organize their care plans and other information into a medical notebook. Having such a summary that includes all medications, contact information for all specialists, a record of hospitalizations and surgeries, and other descriptive information may save heartache and confusion for your family in a time of crisis. It will also be valued by staff at your child's medical home.

Many online examples are available to use as references for medical summaries, action plans, emergency plans and other forms which can be used in a parent's notebook or portfolio. The American Academy of Pediatrics' medical home website is a good comprehensive resource for this (www.medicalhomeinfo.org). As young adults begin to think about transitioning to an adult doctor or adult practice, a transition plan may be created with your doctor or nurse practi-

tioner to provide guidance and support. If you see a format that looks helpful and interesting, talk to your care providers and get their opinion and help to fill out the plan. Make sure that any care plans are written down, placed in your child's medical record or within the electronic medical record, and copied for your use. If your doctor is not available to you or if you travel and need to access medical care, having a care plan will help you and any unfamiliar health care providers.

4. Frame key questions to ask your health care providers

As you learn about what medical homes are meant to provide, you will become an expert in asking important questions of your child's health care team. If you are looking for a new doctor or practice, you might even interview providers at a medical home to assess their strengths in certain crucial care areas. There are tools to help practices measure the strength of their medical home (such as CMHI's Medical Home Index). There are also tools to allow families to evaluate the

continued on page 26

continued from page 24

care that they receive from a medical home (such as CMHI's Medical Home Family Index). Both of these tools are available on CMHI's website (www.medicalhomeimprovement.org). Whether you use the complete tool or draw from the questions to help you make inquiries of the practice, you will find good questions to ask of providers. For example, you can ask doctors and staff whether they use care plans, have family advisors, or communicate effectively with school staff and specialists.

As you become more informed about your "ideal medical home," you may have further questions of your primary care physician. You may ask your health care provider if a care coordinator is part of the team or ask if you could make an appointment without your child to discuss a concern. You may request help establishing a comprehensive care plan for your child. In these discussions you will get a good sense of the ongoing support you may expect, such as assistance with specialty referrals and recommendations. You can share with the practice the efforts you make every day to live positive lives. You will gain insight into the readiness of a medical home to learn from you as an expert in your child's care.

5. Expand Quality Care to Your Community

Effective methods to strengthen the communication among you, your medical practice (medical home) and other health and education providers are always needed. With good pre-planning, your doctor or care coordinator may be able to attend an individual family service plan (IFSP) or an individual educational plan (IEP) meeting (or participate by speaker phone in a portion of the meeting). Their input informs the team about your child's medical needs and provides information and reassurances which is usually quite welcome. This fits well with the medical home aim of providing well-coordinated care including continuity across other organizations. A good medical home includes coordination not only with edu-

catational settings but with pediatric specialists as well. As a parent, you can help promote plans that ensure good communication among all specialists, the medical team, and the team at school. You will want to make certain that the needs of your child and family are central to this planning. Often is your permission is what is needed for others to be able to share important information about your child. Allowing secure e-mail or web based communication and/or putting the different helping professionals in touch with one another fosters continuity across the settings where your child lives, grows, and learns each day. You will need to decide how you want to protect the privacy of your family while considering the possibility of granting permission to others to communicate on your behalf. You will want to consider how you will maintain control over the extent of the information you allow to be shared.

6. Spread Ideas about the Medical Home to other Families

As you meet other parents who have children with chronic or long-term health conditions or disabilities, you will probably discuss many issues regarding care. Parents can be invaluable resources and teachers and have great insights into what constitutes excellent medical care. Asking pointed questions may help you gain knowledge about what works well and what doesn't work well in a medical practice caring for children with special health conditions. You can learn from other parents by asking the following:

- How do they make certain that their child's care is coordinated?
- How do they ensure that the most up to date information is part of their child's chart or record?
- How does their medical home help them with all of the specialists involved?
- How does their medical home relate to their child's educational team?
- How does their medical home help them to get the best information on

available resources such as Medicaid, selecting and paying for supplies and equipment, summer camps, or parent support groups?

- Do they experience good listening, respect, and support in their medical home; in what ways do they experience these attributes?
- Are the cultural beliefs and practices of parents considered and respected?

The answers and ideas heard can be used in a proactive way to help you guide your medical home team to improve. It will also allow you to inform other parents about what to expect from a medical home.

7. Help your Medical Home Staff with Small Improvement Projects

Families who are raising a child with special health care needs provide valuable feedback to the medical home. Learning from parents can take on many forms, such as asking questions through family surveys or focus groups, or gaining ideas from suggestion boxes or advisory groups. If you are someone who is intrigued by the idea of improving your medical home, you may want to explore ideas with the staff in the practice. You can help them to consider "what does this practice do well," "what could it do better," "what should a medical home look like here within one, three, or five years?" Such a dialogue might be well-received and is certain to generate some new ideas. A discussion between you, your child's doctor, and the office care coordinator (if there is one) would be a good place to start. You could call the pediatrician or family doctor and explain your idea. You might help them to invite a group of parents to a brown-bag lunch with medical home staff to explore ideas and innovations. Offering to take on a small project around a special topic (such as creating a waiting room bulletin board for children with chronic health conditions or collecting resource materials for the practice) may help you and the staff to

continued on page 28

continued from page 26

get comfortable working together. Once your group has decided what the needs are, write down a few paragraphs about what you would like to do (a proposal) and bring it back to the practice. Ideally, the focus of your small project will be on helping families who have a child with a chronic health condition, rather than on the administrative aspects of the office.

8. Join a medical home improvement team as a “parent partner”

Having families take a partnership role within a medical home and contribute to the team’s improvement of healthcare delivery is a new idea. If you are tempted to take on the role of a “parent partner”, there is some general information that can be helpful for you. The Center for Medical Home Improvement asks practice teams who want to improve their medical home to invite (at least) two parents/family members to join the team as Parent Partners. These parents are joined in their effort by a committed lead physician and someone who can develop into the role of a care coordinator within the office.

Typically a medical home improvement team first designs a method to identify children and youth in the practice who have complex or chronic conditions or disabilities. This helps the team to organize and provide better care for a specific population. Knowing the population of children and youth with special health care needs (CYSHCN) helps the team in numerous ways. For example, when they see that a patient has special needs they can schedule longer appointment times; they can review records and be better prepared for the visit; afterwards they can provide more thorough follow up around set goals. The work of a medical home improvement team is to look at what they are trying to improve, for whom, and how they will determine that they have made an improvement. There are many changes that will enhance the care experience and improve health outcomes for children, families and the practice. The team will

need to evaluate whether changes are indeed helping. Behind the scenes, health system oriented improvements may be necessary (such as securing reimbursement for the time needed to provide comprehensive quality care for CYSHCN).

9. Reach out to other parents on behalf of the medical home team

Your ideas may turn into actions that will help other parents in the practice. There are many opportunities to provide support and information for other parents. The practice can play a collaborative, helpful, leadership role in creating these opportunities. For example, the practice could host learning sessions with the state Parent Information Center/ Parent Training Center. Or they can sponsor speakers on special topics such as Attention Deficit Hyperactivity Disorder (ADHD) or transitioning from early supports and services to preschool. The medical home can help find, host, and/or offer space to family group meetings. They can invite speakers (including parents) knowledgeable about specific chronic conditions in childhood and/or about improving the medical home. In your role as parent partner you may want to gain the input of a broader group of families. You can be the liaison making certain that the voices of many families are heard at the practice and that the medical home team is working to meet their needs. If you are interested in learning more about the role of Parent Partner go to www.medicalhomeimprovement.org and click on Parent Partner Guide under resources to find CMHI’s Parent Partners: Creative Forces on Medical Home Improvement Teams.

10. Evaluate continuously and design new medical home improvements

As you evaluate your medical home efforts, you will be able to use what you learn from your improvement experiences to form future “next steps”. Medical home improve-

ment teams are dynamic. As you design improvements and try them out, you will learn or think of even better next steps. Continually learning and using that knowledge to help the practice better meet the needs of children and families will strengthen the quality of your medical home. Opportunities to learn from other medical homes need to be found and taken advantage of; there are many statewide efforts to help make this happen. This continuous learning keeps momentum moving forward so that medical homes will continue to improve how they meet the needs of children and families.

Summary

There is much to learn about quality care in a medical home and what activities and services make up such care. Once you learn what great medical homes can offer, you will probably want care improved for your children and family. You may want to pro-actively ask for these services as well as find ways to ensure that all families have access to effective medical homes. You can effect changes for your own child by educating yourself, preparing for visits, eliciting a higher level of care coordination, and asking the relevant medical home questions. Whether you choose to step gently or more boldly into the medical home arena, your choices are bound to make an improvement for your child and potentially your greater community.

If you choose to get involved on a larger scale, you may help the office/practice with short term projects, expand care into the community, spread ideas to other families, join a medical home team, or reach out to other parents on behalf of the medical home team. The health professionals will be grateful for your input and energized by your ideas. As with other medical home partnerships that have gone before you, your team will find ideas and energy to improve your medical home and the care of all children and families. You will see your best ideas and efforts spread as others attempt to replicate the satisfying and rewarding strategies within their own medical homes and communities. 