



# PARENT PARTNERS

Creative Forces on  
Medical Home Improvement Teams

*A Guide for Parent and Practice “Partners”  
Working to Build Medical Homes for  
Children with Special Health Care Needs\**



Center for Medical Home  
Improvement (CMHI)

\* An addendum to the Center for Medical Home Improvement’s Building a Medical Home:  
Improvement Strategies in Primary Care for Children with Special Health Care Needs



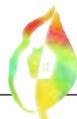
## ACKNOWLEDGEMENTS

First, I would like to thank the parents of children with special health care needs who have dedicated so much time and energy to create change in their children's primary care practice and who have shared their insights for this guide. These parents truly inspire deep and lasting change. Secondly, my appreciation and thanks to the dedicated Practice Partners who believe in the Medical Home concept and who champion parents as change agents in their practice. These professionals have set the bar high for other primary care practices that care to follow. They are wonderful leaders and skilled practitioners who care enough to take a hard look at their practice and find ways to improve it. Lastly without our leaders for Medical Home improvement – Jeannie McAllister, Jessy LaValley, Carl Cooley and Sandi Cragin at CMHI – our families and children would not have had the opportunity to participate in these exciting efforts. We Parent Partners are indebted to you for your insight and drive to accomplish change and for your efforts to share your visionary ideas throughout the country.

Ann Donoghue Dillon

This guide was developed by Ann Donoghue Dillon in collaboration with the Center for Medical Home Improvement (CMHI). It was edited by Jeanne W. McAllister, Jessy LaValley and W. Carl Cooley. Ann is the mother of three children, one of whom has special health care needs. She is an occupational therapist and a professional educator in the health field (employed by the IOD/UCEDD University of New Hampshire). Ann also has six years experience as a Parent Partner with Exeter Pediatric Associates, Exeter, New Hampshire.

Support for this resource comes from the United States Maternal and Child Health Bureau 5 H02 MC00087-02





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## I. INTRODUCTION

Across the nation numerous primary care practices have been working to integrate the Medical Home concept into their daily routines for providing care to children with special health care needs (CSHCN). The United States Maternal and Child Health Bureau, Division of Children with Special Health Care Needs has developed an action agenda for improving care. Included in this agenda is the goal that all children with special health care needs will receive care in a Medical Home by 2010. Parents and professionals agree that there is much work to be done. The Center for Medical Home Improvement (CMHI), at The Hood Center for Children and Families, works with primary care practices to improve their “Medical Homeness” utilizing a quality improvement team approach. Practices are challenged to look at the gap between how they would like care to be and how it actually is, and to design ways to improve the quality of care for children with special health care needs/all children. The team approach used engages staff members (a lead physician, a care coordinator) and parents as key improvement partners. Together these teams generate ideas, test them in practice, and ultimately redesign how a true Medical Home provides care in partnership with families.

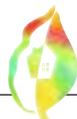
This guide has been developed to define and describe the role of the Parent Partner on the Medical Home improvement team. It offers insight into how practices and interested groups can learn about engaging Parent Partners in their efforts to “build” strong Medical Homes. Methods and strategies compiled over the past five years from numerous “Medical Homes” are organized into a comprehensive guide for interested teams.

To parents, a Medical Home is a place where they know care for their child is centralized, coordinated and monitored. Physicians and staff create a “hub”, collecting and disseminating information and best care practices on behalf of children in partnership with their families. A Medical Home is also a place where “everyone knows your name”; both children and family have the additional support of a practice-based care coordinator; and clinicians go the extra mile to collaborate with specialists and therapists to coordinate care.

To professionals, providing a Medical Home means offering care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (AAP, Policy Statement, July 2002). This is a challenge in today’s health care environment, yet many examples demonstrate that as a result of the teamwork of Parent and Practice Partners, it can be done.

As a parent who became a Parent Partner in a pediatric practice six years ago, the distance traveled between my first introduction to the concept of the Medical Home and the present reality has been a winding path full of insights, rewards and challenges. When recently approached by the CMHI staff to collaborate on the development of a Parent Partner Guide, I enthusiastically agreed. It is a journey well worth talking about.

“Would you like to be part of a new Medical Home project?” When asked that question six years ago by a staff member at my children’s primary care office, my first impression was one of skepticism. After all, I did everything in my power to keep our home from looking like a Medical





Home! In place of an IV pole in my daughter's bedroom we used lengths of ribbon tied to the bed post. We color coordinated my daughter's adaptive equipment to match the children's furniture in our family room. We are proud of the fact that our home looks like a typical home, not a "medical" looking home. Of course, my initial impression was far from the actual meaning of the concept! If you are a Parent Partner learning about "Medical Home" for the first time, perhaps you can relate to my very erroneous misunderstanding! If you are a Practice Partner, you may also appreciate my confusion over what the true meaning of Medical Home was and is.

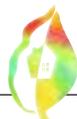
Medical Home is a complicated concept to define or describe to those unaware of its origins or purpose. Even more challenging is trying to describe how Parent Partners play a vital role in making the Medical Home concept become a reality in an office practice. Unique personalities of both professionals and parents create interesting dynamics on newly formed improvement teams. As a result an array of Medical Home characteristics develops. Interpersonal skills, backgrounds, and the ability to work in a group also contribute to this unique mix. Each team will have a different experience (slightly or even drastically) from the next. In the pages that follow a collection of thoughts and ideas that can help parents learn about their new role are suggested. These thoughts and ideas should also help practices as they invite parents to be their partners and seek ways to support their ongoing involvement in the improvement process.

I hope you enjoy and learn from this guide. Soon the guide will need to be updated to reflect new and innovative suggestions that result from your role working with or as Parent Partners.

Ann Dillon, Parent Partner  
Exeter Pediatrics Associates  
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Exeter Pediatrics, Medical Home Improvement Team  
Greg Prazar, MD; Ann Dillon, Parent Partner; Jody Couillard, Care Coordinator and  
Nancy Hadley, Parent Partner





## II. STEPS TO MEDICAL HOME IMPROVEMENT: CHOOSING PARENT PARTNERS

**The best thing you will ever do for your practice!**

Physicians and care coordinators involved in the Center for Medical Home Improvement's practice improvement efforts have shared both their positive ideas for partnering with parents as well as their candid reservations about choosing parents to enter into this partnership. Their feedback has been invaluable.

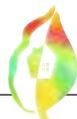
Choosing a Parent Partner for the first time involves three steps:

- 1) Helping Practice Partners understand and embrace the idea of engaging parents of CSHCN as partners
- 2) Discussing the parental traits, qualities, and characteristics that would complement the team
- 3) Successfully selecting a Parent Partner by discussing specific practice parents and determining if they would be a good match for the team

After selecting the Parent Partners and inviting them to join, you can invite them to meet the Practice Partners, orient them to the Medical Home concepts and the improvement process, and begin the team process of designing changes for effective medical home improvement.

### *Step 1: Embracing the Idea of a Parent Partner:*

As a Medical Home Improvement team begins to form, the Practice Partners may need to discuss, or even grapple with, the concept of having parents as true partners and equal team members. Some will embrace the idea without reservation; others will need to be convinced of the significant value to be found in redesigning care in partnership with parents. An improvement team cannot address issues of quality without input from the very customers (parents and children) that directly benefit from the services offered by the practice.





## *Step 2: Discussing Characteristics, Traits, and Qualities:*

In Section III, we fully address some of the possible gifts and attributes that will be helpful in a Parent Partner. Your team should discuss these points and determine what collection of characteristics best meets your needs. A few pointers:

- You want to invite a parent who is:
  - ready to step into this expanded role
  - who has time (and access to childcare) to commit
  - who is a good group member/player, and
  - is able to speak up in a group
- A parent experienced with local resources and multiple specialists will be an asset.
- Virtually all teams mention a sense of humor as extremely helpful!
- Some practices have made a conscious choice to invite a Parent Partner who would not challenge them “too much” at the beginning. As time went on, confidence grew. Now they may need a new parent and find they are ready for someone who would indeed challenge them a bit more.

*“Our team meets 1-2 times per month for ninety minutes. We have a physician, care coordinator, 2 parents and a facilitator as our core members. Other office practitioners join us from time to time; usually this is related to specific tasks or topics. Parents are paid \$12 per hour. Our team members alternate roles of leader, note taker, timekeeper, and facilitator when our facilitator is unable to join us”.*

*—Nancy Hadley, Parent Partner*

## *Step 3: Successfully Selecting a Parent Partner:*

Finally, ask other clinicians in your practice (if available) to suggest parents who fit your wish list. Nurses, nurse practitioners, practice managers, and receptionists often have repeated contacts with families and may also have ideas of who stands out as a match for your desired characteristics. Discuss your options for possible Parent Partners within your developing Medical Home team and then take the final step of inviting them to join you in your efforts.



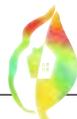


### *Step 4: Inviting and Compensating a Parent Partner:*

Be ready to inform potential Parent Partners about the time commitment (usually one or two meetings per month, plus an occasional full day retreat/meeting) and the stipend they will receive for their contribution (if any). When a for-profit group seeks the advice of a consultant, it is customary to compensate them. Parents as consultants may receive \$12-\$25 or more for their time and effort. Every practice will certainly vary. Have available any Medical Home explanatory information that may support your intended Medical Home vision. You may even offer to connect new Parent Partners to Parent Partners in other practices so that they can do some parent-to-parent investigating. This will deepen their understanding of this role before they make a final commitment.

### *Step 5: Replacing a Parent Partner:*

In some instances, a Parent Partner may need to withdraw and your team will want to replace him or her. In this case, the team will usually forgo the first step of discussing the importance of parents as partners as you already have this history. The second step – discussing what kind of parent would compliment your team – should be much easier as you have already experienced what does and does not work on your team. You may see gaps in your team skills that could be filled by your new parent. The third step – talking about specific parents with other providers – is worth repeating as new families will have joined your practice and your office partners may have “the perfect” Parent Partner just waiting for your invitation. You may have originally asked parents who were unable to participate at that time; it is worth considering those parents again as they may now be available.

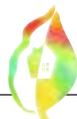




### III. QUALITIES AND QUALIFICATIONS, GIFTS AND TALENTS: THE MANY FACES OF PARENT PARTNERS

Parents of children with special health care needs are as diverse as any other group of people. As you can imagine, the parents chosen for CMHI Medical Home improvement teams have been varied too, often as different as night from day. While there certainly is no one ideal Parent Partner that would complement every practice, there are many qualities, gifts and talents that may be helpful in making your team work efficiently together. Following is a list of qualities to consider.

- Parent Partners need to have a child with a disability or chronic health condition. Ideally, you could pick two parents whose children experience different disabilities or conditions. This may offer the team different perspectives. The parent should be well enough established on their journey with their child(ren) to be able to look beyond their own issues and concerns and consider ideas from the perspectives of other families. As their children get older, parents may access a wider variety of services and supports and that can be very helpful to the team.
- Parent Partners need to understand that this is not a support group for them and that simply telling their story may not be what the group needs in order to move forward with improvements. Consider a parent who is not overwhelmed with their current situation and has energy to be part of this type of working group.
- Parents who have experience with a variety of local and state resources and with multiple specialists can contribute and share this knowledge.
- Parents who are ready to put energy into changing the health care system, who have a strong desire to make a difference or a contribution, and are trying to give something back, are good candidates for the team. Consider parents you have met who have good ideas, are constructive, and interested in promoting their good ideas but are also able to work on shared agendas.
- Parents need to commit the time necessary for meetings and (at times) follow-up with “homework”. If possible, it is helpful if they can occasionally attend longer meetings or retreats. Teams that embrace partnerships will find a time to meet that accommodates everyone’s schedule, and this is indeed a huge challenge! Early mornings, lunch times or early evenings may work best. It just depends on the mix of childcare availability, patient responsibilities and other professional and personal obligations. A committed team will work to find the common denominator of these varying time pressures.
- Parents should be able to communicate effectively. Some will have no trouble finding their voice; others may feel intimidated in this role and need the encouragement of the team and/or facilitator. Ideally, parents should be able to voice their ideas and concerns comfortably, and not feel restrained because of fears that they will be judged for something





they might say. Teams that do this well have created a sense of safety so that people don't feel embarrassed or afraid to speak. A sense of trust pervades their meetings and time together.

- Working on a team where the input of every member is equally valued and respected may be a new adventure for your Parent Partner. You are looking for someone who can work at this level of partnership. Think about parents who have sought you out for help but who also have shared their ideas and resources. Which parents have taught you the most about raising and caring for a CSHCN? Teams develop as trust grows among team members; remember that this may take a little time.

### As your team gains more experience...

- A positive attitude can make the meetings more productive and enjoyable. At times, work on a team can get challenging or even discouraging and it is helpful to have prevailing positive attitudes!
- Parents who possess a sense of confidence (so they will not feel intimidated by others at the table) will have an advantage as a team member. Family members need to feel that they are true partners in the improvement process, not just an advisor, but a creative partner. Parents would not want to be perceived as token parents or filling a seat to meet a requirement. Acceptance as an equal team peer by other team members is vital in making this partnership work.
- Again, having a sense of humor, being able to enjoy one's team members, celebrating successes, creating some fun during the meetings - these are all ingredients that make for enjoyable partners and teamwork in any venture.
- Facilitators can help parents understand their role and offer a strong complement to the team. Consider how and from what source your team might secure the help of an objective team facilitator.

After studying the list above, spend some time creating a wish list or profile for your ideal Parent Partner. What qualities, traits and talents are you looking for?

Notes: \_\_\_\_\_  
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#### IV. EDUCATION FOR PARENT PARTNERS ABOUT THE MEDICAL HOME

Initially, Medical Home is a difficult concept to grasp. As an opening exercise at one of the CMHI retreats, a contest was held challenging participants to re-articulate the concept of “Medical Home.” The goal was to identify new phrases that would help everyone better explain the intended meaning. Chosen from among at least twenty entries **Pediatric Care Improvement Project** was the first place winner. Second place winner went to the name **Connection Central** and third place went to a humorous entry, **Bridge Over Muddled Waters**. You can use these and other learned terms to help explain the concept of Medical Home improvement creating a fuller explanation for both Parent and Practice Partners.

Another description of Medical Home comes from a Parent Partner, who explains how she tells others about her work with her Medical Home improvement team:

I don't think I understood how self-directed the {Medical Home Improvement} project was until we were well underway, but it isn't hard to understand that providing services and care to these kids is complex for everyone involved and we all could use some assistance. I tell others that I work on a project designed to develop best practices and tools that will help my child's primary care pediatric office provide high quality care and services to the children with special health care needs. I provide the office with my perspective as a parent, as a consumer, and as a business professional.

—Sandy Julius, Parent Partner  
Hagan and Rinehart Pediatrics & Adolescent Medicine  
South Burlington, Vermont

Education for parents about the Medical Home concept occurs in a variety of ways. Some will want to use the CMHI “Toolkit” or numerous American Academy of Pediatrics brochures and articles suggesting the importance and benefits of having a Medical Home. Others will want to immerse themselves in the team process and learn by doing – contributing at meetings, chatting about Medical Home with others, and learning how it feels to do this work in action. The journey itself is the “textbook”. For most, it will be a combination of the above strategies to solidify their understanding of “Medical Homeness”. Through team time and connecting with others, Medical Home understanding will grow as will the ability to make important contributions. As a general guide, we have included several ideas for how parents can increase their understanding of the Medical Home concept.

*Formal* ways of learning about the intent of the Medical Home (and the need for improvement) may help contribute to a parent's comfort in their partnering role. For some [teams], a retreat or workshop may be the first opportunity to learn about creating a Medical Home. CMHI retreats have offered something for every type of learner and team member. There have been formal lectures, group exercises with charts and graphs, techniques for refining your team's hottest topics





and even game shows and humorous videos to help us learn about other teams and how they define and implement the Medical Home concepts.

These retreats showcase the work of practice teams including examples of a wide scope of activities falling under the heading of “Medical Home improvement.” Creating a packet of useful team tools (care plans, Medical Home explanations, family explanatory letters, focus group question guides, etc) produced over time can benefit other teams who may want to borrow your ideas. A great willingness to share ideas and strategies has emerged from a collaborative group of Medical Home improvers. Having a team facilitator work with each practice site and act as a go-between further enables that transfer of ideas. CMHI facilitators support each practice site thereby helping with the transfer and further development of ideas. The use of electronic technology such as e-mail and resources offered through the internet foster shared learning. Improvement meetings, with their structure, organized format, and alternating roles help teams learn “on the job”. The facilitator is instrumental in connecting a team’s proposed activities to their original aim and action plan, and in this way helps to keep a team on course.

*Informal* means of learning about the Medical Home and making improvements can be just as helpful. When new parents join the team, your veteran parents can take them to coffee or lunch (courtesy of the practice) to get to know each other and establish an informal mentoring of the new parent.

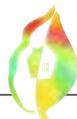
*“Our team has had many long car rides to retreats through the rural countryside. This gave us great opportunities to get further acquainted and enjoy the luxury of talking more informally about the project”*

*—New Hampshire Parent Partner*

During CMHI retreats, ample “down time” for team members to spend with one another is always planned. Such time is invaluable in sharing ideas and having conversations that move in creative directions. At other times it is useful to brainstorm to allow for dreaming, and to get the team thinking outside of the box. This, and sharing a sense of accomplishment, refresh and revitalize a team. These spontaneous events liven up a group and bring new ideas to the surface. Other ways of accomplishing this same outcome include meeting over a potluck dinner or having an early breakfast in someone’s home to rejuvenate, celebrate, and add some diversity to your time together.

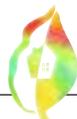
Outside the team meeting, conversations with a facilitator can also help a team. These may be on the fly, after a regular team meeting is over, or even in the parking lot on the way to one’s next commitment. When you are new to a team, it is helpful to have some time to process events or ideas, or to check in on an issue. Spending even a few moments with your team’s facilitator to gain clarity may add to a Parent or Practice Partner’s understanding of the project and/or their Medical Home improvement efforts.

*Written materials* offer helpful educational supports for some parents; for others, too much information can be overwhelming. CMHI has developed the toolkit “Building a Medical Home: Improvement Strategies in Primary Care for CSHCN” and their website





([www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)). These resources are for teams to become better acquainted with the improvement process necessary to develop stronger Medical Homes and to learn from the examples of other teams. Articles on the Medical Home concept can be found within the American Academy of Pediatrics materials ([www.aap.org](http://www.aap.org) and [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)). The literature generates a general sense of meaning for the Medical Home concept, but Medical Home is really best defined and understood as the team works through exercises, overcomes struggles in meetings, and holds breakthrough discussions. These help a team to create its own unique brand or version of the Medical Home. A general Medical Home overview may be gleaned from the literature, but it is the team that really develops and fine-tunes the concept of a Medical Home in its own way for its own unique setting and location.





## V. PRODUCTIVE MEDICAL HOME IMPROVEMENT TEAMS IN ACTION

Picture a snowy New Hampshire morning with team members rushing in from home or the nearby hospital. Jody (care coordinator) carries home baked treats, Greg (MD) brings a beverage to share, Jeannie (facilitator) greets everyone and prepares to help the team review its progress and take the next steps, and Nancy and Ann (Parent Partners) trade humorous stories about their children. There is a warm exchange and a welcoming sense of inclusion. The meeting begins. “Who wants to be Leader?” . . . And so on until all the roles are assigned. “What do we want on the Agenda?” “What items are left over from last time?” “How much time should we budget for each item?” The structure rapidly transforms the energized group into a powerhouse of action, change and creativity. For one and a half hours, the group wades through the items, taking notes on who will do what before the next meeting. Time flies by and the group closes by checking in with each other, doing a quick evaluation/summary of our thoughts. Greg will often say “I look forward to these meetings so much, they are often the best part of my day. This process has transformed the way I practice pediatrics on a daily basis.” Parent Partners say they feel pleased to have the practice listen to their ideas and witness the resulting changes.

The perfect motivation to keep team members invested in Medical Home improvement work is the belief that their work does make a difference to both families and providers. Practical ideas and suggestions from Parent and Practice Partners help teams continue to grow and strengthen in their ability to work well together. The following tips are derived from attending to the details that make this process “work well” for all involved.

- **Scheduling team meetings to fit both a Parent Partner’s work and family schedules with the Practice Partner’s schedules**

This can be a challenge and the solution may be that everyone has to bend a bit. For example, if a parent can’t start until 8 a.m., but others prefer to start at 7:30 a.m., a solution might be to start at 8 a.m. but meet more frequently for shorter periods or alternate times allowing for flexibility. CMHI has teams who meet in the early morning, at lunch, at the end of the day, and even on alternating days and times to accommodate their members.

*“One of our team members often expresses his gratitude for the meeting, saying it is the bright spot in his day. This has had a way of recharging our batteries and motivates us to keep coming back for more improvement work”.*

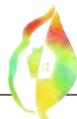
—Parent Partner

- **Flexibility**

In addition to being flexible with meeting times, being flexible about agenda items and tasks may also be necessary to keep your team feeling like the partnership is working effectively.

- **Sharing roles during meetings**

You may want to rotate the roles of leader, timekeeper, and note taker at each meeting to keep a sense of shared responsibility and partnership alive. Rotating these roles also helps develop a sense of equality among team members as well as help increase effectiveness.





- **Evaluative “check ins” at end of meeting**

A technique for evaluating the meeting is to check in with one another assessing how the meeting went. This five-minute evaluation at meeting’s end offers a chance to vent, celebrate, express gratitude and/or create closure. In less than one minute, each group member can get a chance to touch base and may express something that otherwise might get buried. It is not atypical for Practice Partners to believe they are going as fast as they can and for Parent Partners to be frustrated that the pace of change is not swifter. Airing frustration can open the way to creating understanding.

- **Team Process Evaluation**

Sometimes, more time and attention needs to be paid to evaluating the team’s efforts. Informal meetings can accomplish this or the team can decide to take their team pulse every few months. In the body of a meeting, increased time can be devoted to discussing or reviewing your accomplishments and future directions. Completing CMHI’s Medical Home Index and Medical Home Family Index offers a more formal structure for doing a type of annual check-in.

- **Using your voice as a parent**

Parents might be new at using their voice to advocate for a broader group of families or to present viewpoints on practice care issues. The parents can confide in the facilitator, or a trusted group member – they, in turn, may help facilitate improved Parent Partner participation by assisting with parent participation during meetings, or by e-mailing or calling them as a follow up. A Parent Partner can support the team in many ways. Ultimately it is the voice and opinions of the Parent Partners blended with the Practice Partners that are most wanted and needed. With experience and the building of trust, Parent Partners gain confidence to make contributions, and engage in team give and take.

- **Support team members when it gets emotional**

When a team member expresses a strong emotion, other team members can be helpful in their support, encouraging open discussion. Medical Home improvement teams are doing such important work that at times, a burst of insight may be accompanied by strong emotion. For example, parents may help others realize the impact of having a child who has special needs on family life. Parents can also express the significance to them of simple acts of kindness, such as staff remembering special requests or a physician reaching out and participating with particular daily care tasks during a visit, tasks that always fall to Mom or Dad. This is all part of typical team process; take some time to acknowledge strong feelings and then, as appropriate, move on.

- **Helping the team move forward**

Teams may get stuck on a project or stalled on an idea, unable to take action. This can be frustrating. Bringing this to the team’s attention in a challenging yet supportive way may be the catalyst for creating change and helping the group to move forward. Any team member can challenge the group in this way.





- **Finding a balanced work load for the team**

Teams will often create a long list of goals and projects and then feel frustrated when none of them are complete. Similarly, teams may get so bogged down on one topic that they fail to cover many of their intended tasks. Your team needs to discover its own pace and be aware when the pace doesn't match the agreed upon goals and actions. Creating an atmosphere where discussion about pace is encouraged and valued should help team members feel able to raise these issues.

- **Valuing all, celebrating success, appreciating each other**

Teams flourish when they develop a sense of celebration at meetings; this is especially so when a goal is met, a project concluded, or a solution identified to match a dilemma. Celebrate it.

- **Drawing out ideas from other parents in the practice**

Parents have unique abilities to talk candidly to other parents in the practice about their ideas, concerns, and issues. This can be done through casual conversation, questionnaires or through more formal focus groups. Focus groups inform the improvement team of the most important issues for other parents in the practice. Parent Partners represent a significant resource to the practice in this area; many have assisted with leading and/or facilitating such a focus group (or are eager to learn how to do this).

- **Sharing other skills and talents**

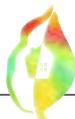
Some parents have specialized skills or talents that they can share with the group. Organizational skills, computer skills, photography, design, business, and facilitation skills all can be an asset. For example a Parent Partner may be skilled at graphic design and help to develop a brochure. Another may be able to help the practice become more technologically advanced. Many parents have brought wonderful organizational skills to their team. Explore the gifts and talents of each of your partners and tap into their skills when they indicate a willingness to help in this manner.

- **Feeling free to be creative and get “off task”**

Being flexible allows parents and other team members to raise issues that were not on the agenda. Appreciating that the issue may not get addressed at that very moment, parents can feel satisfaction that they raised awareness about the issue and can ask to include this discussion at a later date.

- **When it is appropriate to get personal and tell your story**

Having already said that it is desirable for parents to be able to move beyond their own story, it may sometimes be important to the group to tell your story. This may occur when the group doesn't understand something that the parent is knowledgeable about; or when a short family example may help illustrate a point. The group can also ask for specific Parent Partner input on a topic they know the parent has personal experience with; or a Parent Partner can take the initiative when they feel the group needs such personal information to help their understanding.





- **Parent’s role in testing an idea or product**

Another important personal contribution from parents comes when teams are ready to “test” a new product or change idea. For example, parents can help by trying out the new “parent journal” page or care plan or by volunteering their child’s record to implement a new charting idea or to try out a documentation audit.

- **Common Team Dilemmas**

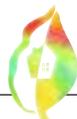
Most parents would probably say that their experiences as a Parent Partner have been overwhelmingly positive. That does not mean that there will not be a few bumps in the road along the way. Some of the most common bumps may include:

- Being overwhelmed, especially at the beginning
- Handling frustrations
- Balancing projects within the team
- Committing to extra work outside of meetings, and
- Balancing family commitments with teamwork

Strategies will be found within the team. A facilitator may offer support; when this is not possible parents should be able to bring up their concerns or frustrations, and with the team, search for solutions.

### **Team Dilemmas – An Example**

A particular team was good at generating lots of creative ideas, but they didn’t seem to have enough time to make them come to life, or make them happen. One team member needed to pull back a bit on her twice monthly commitment due to work and family needs. The solution found was to hold a regular core team meeting once a month and then hold a second meeting with a sub-group of team members to concentrate on implementation strategies. This remedy was a creative “win-win” for all team members.





## VI. “ADVANCED” MEDICAL HOME IMPROVEMENT

As a team evolves they may find themselves discussing deeper issues such as social justice, advocacy in legislation, community access, and partnering with schools. While maintaining a commitment to improving care within the practice, it is possible and admirable to develop a broader agenda that not only taps into the strengths of the group but addresses larger issues effecting the lives of children with special health care needs and their families at the community and state level.

Typically teams will implement many practice improvement changes as energy and momentum build. As this momentum builds the team may develop goals that expand beyond the walls of the building, including engaging the community, contacting policy makers, and working with payers and others. The scope and depth of change ideas is enhanced. For example one team focused on improving child and family quality of life as an aim for their group. One factor in quality of life discussions is being healthy, but there are many other aspects to this topic. Children need a lifestyle that supports friendships, family and community involvement, with choice and control over one’s own life. The concept also relates to the presence of rich relationships, making contributions to society, and experiencing community connections. Parents may have concerns about quality of life but have not engaged the Practice Partners in a discussion of their thoughts and fears. Practice advocacy can help to move an agenda supportive of enriching the quality of life for children and families.

How can your Medical Home team accomplish a goal as lofty as quality of life? Health providers can make a difference by asking just one selected question from a list of questions or options. An example of work in this area includes a team’s development of quality of life questions....

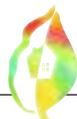
For example, clinicians can ask children and youth the following:

- Tell me about your friends.*
- Or, what after school activities are you involved in?*
- Or, what is the best part of your life?*
- Or, what is the hardest thing in your life?*

Or you could pose similar questions to the child or youth’s parent/family member(s):

- What supports do you have in place?*
- Do you get out as much as you would like?*
- Do you have a plan for transition to adult life and health services for your child?*
- What plans do you have for your child if something were to happen to you or your spouse?*

Medical Home Improvement teams have enormous power to influence change and growth. By opening such doors and discussing quality of life topics during an office visit, many families may consider these issues more fully. Having a practice-based care coordinator to assist the family in addressing such needs will also ensure greater follow-through. Your team could develop a unique list of quality of life questions or prompts and influence families to consider these possibilities.





With the support of caring providers, the challenges that these questions raise could bring about dramatic changes in the quality of life for a child or family. Most parents/families would appreciate being asked these questions and would welcome the family support.

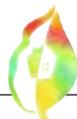
*How easy it would be to have a list of quality of life questions or prompts on the inside flap of the chart (as a reminder or aide to prompt health care providers to inquire about such broader topics).*

*—Parent Partner*

On a community level, teams can contact the local newspaper or town leaders about lack of accessible stores and parking in their downtown. They could also contact legislators about the need for fully funding special education at the national level or about their concern over the length of time on waiting lists for adult service eligibility at age 21.

Teams could implement strategies by adding a question list to the chart, agreeing to jointly write/sign one “advocacy” letter per month, or by inviting family practitioners to partner with them and families to develop effective transition plans. Addressing these issues can ensure that care for children with special health care needs extends beyond the walls of the office and more into daily reality.

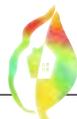
In addition to improving community and health systems, quality of life represents one of many arenas that strong Medical Homes could impact positively.





## VII. SUMMARY

Equipped with the best CMHI has to offer on the role of Parent Partners, we hope you will be energized to create these true partnerships in your/your child's practice. The best advice is to just "do it" and work out the details along the way. It is a journey that will ignite change and transform the primary care practice where your children receive care. At Exeter Pediatric Associates, the improvement team is still involved after six years (and with no plans for slowing down!) Whether your journey is just beginning or well underway, you are wished success and fulfillment as you travel through Practice and Parent Partner changes, discoveries and life changing Medical Home improvements.





## IX. TABLES

The following data is from a CMHI retreat facilitated dialogue with Parent and Practice Partners. Parents were asked three key questions after which Practice Partners had their turn to share insights and lessons learned. Their responses are detailed in Tables 1 and 2.

### *Parents Share Their Thoughts*

<i>When you look back three years from now, what accomplishments will have made you most proud?</i>
<ul style="list-style-type: none"><li>• Incorporating a care plan and portable version for every child with a special health care need</li><li>• A care coordinator for every child</li><li>• The practice supports the position of a care coordinator</li><li>• There is reimbursement for care coordination services</li><li>• Families get matched with other families to offer support</li><li>• The practice listens and responds to the parent point of view</li></ul>
<i>What keeps you (parents) coming back to improvement team meetings?</i>
<ul style="list-style-type: none"><li>• Each time I come back we are putting one more piece in the puzzle</li><li>• I'm motivated to do something for my child</li><li>• I've been listened to</li><li>• I'm doing something for all children with special health care needs</li><li>• Our accomplishments keep me coming back. They motivate me to do more</li><li>• Being involved long enough with the team to start tackling bigger issues</li><li>• I like seeing things get finished</li><li>• The pediatrician's enthusiasm!</li><li>• The positive energy and support from the rest of the practice</li><li>• I look forward to the great snacks</li><li>• The facilitator!</li></ul>
<i>What makes you (parents) feel valued by the practice/Practice Partners?</i>
When: <ul style="list-style-type: none"><li>• My thoughts and suggestions are appreciated</li><li>• Changes are made due to parental input</li><li>• My input is respected and valued</li><li>• I'm seen as an equal partner and expert</li><li>• My perspective and knowledge helps the team learn</li><li>• The team draws things out of parents</li><li>• The team goes with the parents instincts</li><li>• We help providers learn our language and they help us learn their language</li></ul>

TABLE 1. Parent Partners Reflect on Medical Home Improvement Teamwork





## *Practice Partners Speak Out*

### *How do the “Practice Partners” ensure the team’s vision is realized?*

- Make sure the care coordinator survives
- Negotiate with payers to make sure the care coordination gets reimbursed
- Educate staff about the role and skills of a care coordinator
- If project ends, make sure that Parent Partners remain involved in practice improvement
- Make sure that children have a smooth transition to adult care
- Make sure MDs are skilled in providing health care to people with disabilities and special health care needs

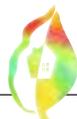
### *How have “Parent Partners” changed the way care is provided?*

- I now see the family as a whole – as one unit
- I focus on the family’s agenda and office visits are improved as a result
- Now I see the real issues for families outside of the office visits; our visits are now broader and deeper
- I understand more about family challenges, frustrations, and the need for respite care
- Every family is different and has different obstacles
- I recognize the importance of communication with schools, establishing links, partnering
- Parents have had positive feedback for the practice and that has impressed and energized the MDs

### *How do you (Practice Partners) let parents know they are valued?*

- We show them that we listen to what they say
- It “makes my day” when we have our meetings and I tell them so
- We use their information and put it into action, incorporating their ideas
- We follow through on requests made by parents
- We are open and honest with parents
- We care enough about their needs to offer them care coordination
- We acknowledge that parents always have difficult choices to make

**TABLE 2. Practice Partners Reflect on Medical Home Improvement Work with Parent Partners**





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