“Extra-Ordinary Care: Improving Your Medical Home”

A Learning Guide: for Families and Caregivers

CMHI (Center for Medical Home Improvement) 2008
Acknowledgements

This Learning Guide supports the learning module “Extra-Ordinary Care: Improving Your Medical Home” which has been created by the Center for Medical Home Improvement with partners from the Institute on Disability University of New Hampshire/University Center for Excellence in Disability (UNH/UCED) and New Hampshire Family Voices.

Funding has been provided through a grant from the Maternal and Child Health Bureau; Integrated Services Division, Health Resources and Services Administration (HRSA) (Grant #H02MCO2613) and New Hampshire Special Medical Services Bureau, Health and Human Services to the Center for Medical Home Improvement (CMHI), Crotched Mountain Foundation, Greenfield, New Hampshire.
Introduction

This Learning Guide is designed to assist families and others in their education about the basics of “medical home”. It also suggests specific activities one can use to strengthen their medical home or advocate for stronger primary care services. As you read through each slide, the Learning Guide provides a brief explanation and helpful hints and tips. If you have a teaching facilitator, he/she will review the slides with you and provide additional information.

Slide 1

WELCOME to the learning session titled “Extra-Ordinary Care: Improving Your Medical Home”.

The following handouts are available in in the back of this Learning Guide:

Appendix A: Definitions of commonly used terms
Appendix B: Companion Materials
  • Sample (blank) care plan
  • “Building a Stronger Medical Home: Questions to Help you Partner with Your Medical Home.”
  • Evaluation form

Available to download at www.medicalhomeimprovement.org:
  ♦ Article ‘Do You Have a Medical Home?’ (Dillon and McAllister)
  ♦ Parent Partners – Creative Forces on Medical Home Improvement Team (CMHI, 2003)

{UNH/UCED - University of New Hampshire/University Center for Excellence in Disability}
{HRSA - Health Resources and Services Administration}
The purpose of this learning session is to provide you with an overview of the medical home, what you can do to help strengthen your medical home, and ways to advocate for a stronger primary care medical home. At the end of this learning session, you will understand the term “medical home”, gain an understanding of what you can do to promote improvements, and identify helpful roles you can take.

Tips

- Ask questions!
- The Medical Home can be confusing. Ask for help understanding what this means.
- As you go through this learning session, think about ways your medical home can be improved and how you can help make this happen.

Notes:

_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
Slide 3 helps to define the population of children and youth with special health care needs. This will help to lay the foundation for the learning session. It may come as a surprise to you which conditions are actually included in the federal definition of children/youth with special health care needs.

Adults typically have one of five or so common chronic health conditions. In children’s health there are well over 200 different chronic health conditions, many can be quite rare.

Approximately 1 out of 5 homes in the United States has a family caring for a child or youth with a special health care need.

Improving the practice for children and youth with special health care needs goes a long way to improving the practice (medical home) for all children.

Children and Youth with Chronic Health Conditions or Special Health Care Needs...have:

- A physical, developmental, behavioral or emotional condition
- Requires health & related services of a type or amount beyond that required by children generally
- Lasts greater than 1 year
  - Examples: Cystic Fibrosis, asthma, cancer, Down syndrome, autism, arthritis, diabetes, bi-polar disorder, seizure disorders, Cerebral Palsy, ADHD, rare genetic conditions, etc.
- Affects about 12-15% of all US children

(USMCHB, 1997)

{USMCHB - United States Maternal and Child Health Bureau}
Slide 4:

The term medical home may be a new or confusing term. This slide is intended to help create a better understanding of the medical home by discussing the idea of a *chronic health condition*.

Can you answer “yes” to any of the following questions?

(In a roomful of people, most hands would be raised when responding to these questions).

---

**Audience Poll**

➢ Raise your hand if you …
   • Have a health condition that has lasted longer than 1 year?
   • Have a son, daughter/ loved one who has a health condition?
   • Work in a medical or health related field?
   • Work in an educational setting?

---

**Notes:**

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
Slide 5:

This slide is helpful in further de-mystifying the term Medical Home. Hearing what the medical home *isn’t* is helpful in further understanding what *it is*.

1. What are you thinking when you hear the term medical home?
2. Note some of the ideas that others have had when hearing this term.

![Medical Home - What are you thinking? We hear many ideas such as:]

| A house with lots of medical equipment? |
| Residential Facility? |
| Medical Equipment Store (Medical Home Depot)? |
| Accessible vacation homes & builders |

Write down what you think a medical home is:

________________________________________________________________________________
________________________________________________________________________________

Notes:
________________________________________________________________________________
Slide 6:

As with slides 4 and 5, slide 6 is to further clarify what a Medical Home is. The following definition is used by the Center for Medical Home Improvement.

You will learn more in the next few slides about what this means, how doctors and nurses provide this kind of care, and ways in which the medical home can work for you.

It is important to note that a quality medical home (as the definition describes), combines people, process and place. It is the central place where primary care is provided (the “where”), the process and scope of care in that place (the “how”), and the team of people delivering and coordinating care (the “who”).

Medical Home is the quality model for 21st century primary care

➢ A medical home is a community-based primary care setting which provides and coordinates high quality, planned, family-centered:
  • health promotion
  • acute illness
  • chronic condition management

(CMHI 2008)

Medical home combines people, process and place

{Health promotion, acute illness and chronic condition management definitions are provided in Appendix A “Definitions of commonly used terms”}

Notes:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
Slide 7:

This slide provides a more in depth discussion about what a medical home is meant to offer for patients and families. **When you have a great medical home, it shows. It is your “go to” place.** But what does this mean?

It **combines people** by creating a team (Team can include youth, family, primary care provider, specialist(s), care coordinator & others.) of people delivering and coordinating care.

It is the **process of how care is provided**, a great medical home:

- **Knows its population**: The practice has ways to identify children/youth who need “extraordinary care”. They know their population of children and families.
- **Partners with and learns from youth and families**: Some practices have advisory councils or a few parent/youth partners who they look to for ideas.
- **Uses a proactive team approach**: Staff works as a team within the practice and with community providers and specialists who also provide care.
- **Connects with other organization**: Staff know the area resources staff members, what they do, and how to make referrals to them.
- **Offers safe, efficient care while preventing duplication**: These activities flow naturally when a practice 1) knows their patients, 2) works as a team, and 3) tracks and monitors care.

Dr. Carl Cooley, Medical Director at the Center for Medical Home Improvement challenges practices by declaring “You already are a medical home… it is up to you how great you want it to be?”

### What Does Medical Home Mean?

**Combines**

**People -The team (includes youth and family)**

**Process - how care is provided**

- knows its population
- partners w/ & learns from youth/ families
- uses a proactive team approach
- connects with other organizations
- offers safe, efficient care

**Place – your “go to” home base, where you receive primary care**

### Tips

- Some examples to illustrate how a practice “knows their population” - 1) when a family calls, the receptionists types in who is calling and an alert pops up on the computer screen to inform staff that the child has a special health care need; 2) Charts are color coded as a reminder.
- A good example of a “proactive approach” is the development of a portable care plan including an emergency plan.
- Care plans/medical summaries and emergency plans are discussed in greater detail in slide 17 pg 19.
Slide 8:

The Family/Child/Youth is at the heart of the medical home. A typical example of how families interact with their medical home might include … a simple relationship among a family, their physician, and family and friends. A “picture” of the medical home might look like the picture in slide 8 when the family sees their child’s primary care provider for:

- Well child checkups, immunizations, and the occasional cold or ear infection.
- The doctor, nurse or physician assistant answers questions and concerns, informs parents about child development, and builds a relationship with the child/youth.

For young children, day care providers may be a part of the child’s care “team”, supported by their family and friends.

Tips
Please observe that in this slide, a typical child goes to their medical home for well child check-ups and the occasional illness visit.

{Definition of medical home, primary doctor and care coordinator are each provided in Appendix A “Definitions of Commonly Used Terms”.

Notes:
________________________________________________________________________________
________________________________________________________________________________
Slide 9:

The complexity (or picture) of care changes dramatically when a child/youth has or develops a chronic health condition. For some children, a medical home may change quickly to look like the picture in the slide below. In fact the medical home may look different for each child, depending on the needs of the child/youth and family. Note the number of people involved in the life of a family when their child/youth has a special health care need. A couple of key points:

- Given the number of people this family interacts with, you can imagine that the staff at this medical home have a lot more contact with the family than in the previous slide.
- The medical home care team is critical to supporting the family as they navigate through all of these supports and services. The team helps to make certain that the care of the child and the needs of the family are met.

Take a moment and count the different communication lines that need to occur. Note the different connections between specialists to family, to primary care, to school, to each other.

This slide illustrates the need for a strong centralized hub with coordination support at the level of the primary care office. In other words, the medical home is the “go to place.”

**Tips**

Please observe that in this slide you are actually viewing a medical home map designed by the mother of a child and youth with special health care needs.

{EI - Early Intervention, OT - Occupational Therapist, PT - Physical Therapists, SLP - Speech Language Pathologist, CYSHCN - Children and Youth with Special Health Care Needs}

**Exercise Slide 9:**

It may help to make an illustration of your child’s medical home by drawing or using tinker toys and/or play dough. Share your medical home design. What do you need to happen here?
Slide 10:

“What does living a full life mean to you?” When looking at the definition of a full good life for children, it usually means having their needs met in all of these areas … community, school, social/friends, family, healthcare, and other.”

People living a good or full life share the need for several basic elements. Just as friends, family, and the love and support of the community are vital to living a good life, so is a healthy body and mind. If children have unaddressed health issues or poor health care, they may not be able to fully participate in their community or have the energy to do so. Living a full life means, in part, growing up healthy.
Slide 11:

This slide helps you think about the quality of care and to “measure” your perception of the care you or your child receive. Go ahead and try to rate your own medical home or medical practice by writing a mark on the green line below each section. {Note: If you are learning with an instructor, you will use your arm like a dial from left to right} “not much” is to the left and “a lot” is to the right, with “some” in the middle.}

You now know how to rate some of the finer points of the quality of care you receive! Does it look like there is room for improvement?
Slide 12:

You now know a bit about the medical home and how to think about the quality of care provided. This may have given you some ideas about things you would like to see change. It may require a mind shift for you – that you have a right to expect more.

A doctor once said the following as she stood in the front of a roomful of expectant mothers. "'Remember, we work for you. Your insurance company works for you, and you pay us'". The message here is that you have a right to expect the services that you need, and you have to give yourself the permission to ask for them.”

The second part of the slide on this page is to emphasize that you have a responsibility to be a partner in care:

- As the constant in your child’s life, the person who knows your child best, you bring a unique perspective and special expertise to your child’s medical team (just as you do to a special education team at school if you have one).
- In order to increase the “medical homeness” of your child’s practice, you have to have high expectations. You have to ask for what you need and partner with your provider to make it happen.

Believe you can increase the “Medical Homeness of your practice”

- You have a right to:
  - Have high expectations
  - Be respected for your input
  - Ask for what you need
    - Information
    - Resources
    - Support

- You have a responsibility to be a partner in care

Notes:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
Slide 13:
There are many things you can do to help improve the quality of care in your medical home.

This learning session will be used as an opportunity to highlight the first 4 ideas on this slide. In the next couple of slides, you will gain skills in learning about your role, preparing for an appointment, and shaping and using care coordination services (when available).

To learn more, you may want to read “Do you have a Medical Home” on CMHI website (http://www.medicalhomeimprovement.org).

10 Ideas to Increase “Medical Homeness”
Continuum, choices, one or all ten may resonate!

1. Learn your role in medical home
2. Preparing for your appointment
3. Shaping your appointment
4. Form partnerships for care coordination
5. Expand care to your community
6. Spread ideas to other families
7. Assist in small projects
8. Join a medical home improvement team
9. Reach out to other parents
10. Evaluate your work

Tips
All too often, families may feel it is difficult to ask questions of their care providers, or to ask for more of their time. Remember, you have a right (and responsibility) to ask.

What would you like to ask?
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Notes:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
You may want to do a little reading to learn more about the medical home. Check out the websites listed on the slide. Exploring various websites will assist you in learning how the medical home is being promoted at the state and national level.

1. Learn Your Role in Medical Home

- Develop an understanding of the medical home concept
- Read/Research
  - [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)
  - [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)
    - Parent Partner Guide: Creative Forces on Medical Home Improvement Teams
    - Do you have a Medical Home?

Tips

Bookmark on your computer your favorite “Medical Home” website.

Notes:

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Exercise Slide 14:

Go to the websites listed above. Explore the various drop down menus and materials available. What 1 or 2 items do you find most helpful? Bookmark your favorite places or list what you want to remember for future reference.

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
2. Preparing for Your Appointment

- Be proactive in setting up the appointment
- Ask for specific support for your child (for example):
  - Ensure front desk is aware of needs
  - Quick placement in quiet, distraction-free room
  - First AM or PM time slot
  - Longer visit
  - No visible needles
  - Ask for visit without your child, if needed
  - Check if specialist’s reports have arrived

Tips
A family that prepares and asks for the items listed on this slide increases the likelihood that they will get what they need. It may help the practice to think about how it delivers services on behalf of other families. Remember you are partnering and working with your medical home. This may be new and will need to be introduced to the practice in a non-demanding way.

Notes:
________________________________________________________________________________
________________________________________________________________________________

Exercise Slide 15:
Read the handout “Building a Stronger Medical Home: Questions to Help You Partner with Your Medical Home.” Select 2 or 3 questions from the handout that are the most important to you. Bring these 2 or 3 questions with you at your next appointment.
Slide 16:

In the last slide we just learned about the things you can do before your appointment. Now we are going to discuss the simple concrete things you can do during an appointment. That is how you can partner with your doctor or nurse in order to make the most of the visit.

Read the bullet items on the slide.

Doing these activities helps to make the best use of your visit time, and helps you become an active partner in your child’s care.

3. Shaping Your Appointment

➢ For the visit
  • Bring:
    • New information
    • Forms
    • Prescription refill requests
  • Write down important questions /concerns

Tips
  • Remember to bring the 2 or 3 questions you selected from the handout “Building a Stronger Medical Home- Questions to Help You Partner with Your Medical Home” to your next appointment.
  • Ask your provider these important questions.
  • To further organize medical appointments go to the AAP website for sample tools (e.g. care notebooks) www.medicalhomeinfo.org/tools/.

Notes:__________________________________________________________________________

Exercise Slide 16:

Go the AAP website www.medicalhomeinfo.org/tools/.
View the care notebooks on the website.
Develop your own care notebook.
Slide 17:

This slide promotes partnerships with staff at your medical home who help coordinate your child’s care. Key in forming this partnership is: 1) developing a care plan, medical summary, and/or emergency plan (if needed); and 2) Transition planning (as your child matures, they may need to transition to an adult doctor).

**Have you heard the term care coordinator before?** A care coordinator is often a member of the practice team. They are a tremendous asset to families and practices. A care coordinator can be a nurse, social worker or other staff member who can assist you with getting special supplies, connect with outside agencies or clinics, and/or help with school concerns (among other services).

Some practices will have a care coordinator, others will have a staff person who sometimes functions like a care coordinator. (Some may have neither.) Ask your practice if there is someone in this role and how you can contact him/her. Partner with your care coordinator or physician to develop a care plan. See the example of a care plan in your handouts. This tool captures the big picture of care for the child (patient). Care plans also help if you need emergency care while out of town – you will have a summary at your fingertips.

As your child grows up, you may need a plan for transitioning to an adult doctor. In transition planning it is important for youth to take more ownership in their care.

---

4. Form Partnerships for Care Coordination

- Ask your physician if there is a nurse or social worker who can help you coordinate care and contact them
  - Work together to develop a plan of care (examples):
    - Care plan/action plan
    - Medical summary
    - Emergency plan
  - Develop transition plan (if needed)

---

**Tips**

- Even if you do not have a care coordinator, knowing about some of the tools available to help coordinate care will be beneficial.
- When you partner with your medical home, you provide an example of how families are great leaders in the medical arena.

---

**Exercise Slide 17:**

Spend 5 – 10 minutes getting started on developing your care plan and/or emergency plan. Use the blank handout in the Appendices as an example. And/or go to the American Academy of Pediatrics website for sample tools: [www.medicalhomeinfo.org/tools/](http://www.medicalhomeinfo.org/tools/).
Slide 18:

This slide is an important reminder that there are many opportunities to develop leadership skills in the medical arena. Note the various opportunities listed on the slide.

Family leaders participate in creating system changes in education, advocacy and legislation, family support, and health care. They serve on boards, run organizations, support families who have children with medical issues, and work to make positive changes!

---

**NH Leaders Are Making a Difference!**

- Center for Medical Home Improvement efforts in Pediatric and Family Medicine practices
- NH Leadership Education in Neurodevelopmental Disabilities (LEND) Graduates
- Bureau of Special Medical Services
- NH Family Voices
- Dartmouth - CHaD
- Council - Children & Adolescents Chronic Health Conditions
- Parent to Parent Coordinators
- Special Councils in regions
  - NH Council on the Future of the Primary Care Medical Home (CMHI)
  - NH Primary Care Task Force (CMHI)
- Other Places…?

---

**Exercise Slide 18:**

If you would like to become more involved check-out the resources listed on the slide.
- Explore New Hampshire Family Voices website: www.nhfv.org

List the opportunities you would like to become more involved in.

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

Set goals. I would like to do ________________________________ by (date)________________________. 
Slide 19:

Similar to the last slide, this slide also helps you think about different opportunities available to increase your knowledge and experience of medical home concepts.

Read the different examples listed on this slide for how you can help advocate/promote the medical home.

How Can You Help Medical Home Efforts?

➤ Learn about the medical home in order to advocate (for it) with families/practices
  • Examples:
    • Become or work with a Care Coordinator (CC)
    • Elicit CC support for families
    • Invite CC to Early Support Services (ESS) or Individual Education Plan (IEP) meetings
    • Tap into CC for resources
    • Foster communication across family & professionals
    • Collaborate in sponsoring a speaker or education
    • Assist in securing family to family support /groups

Notes:
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Exercise Slide 19:
From the examples listed on the slide above, what would you like to become more involved in?

________________________________________________________________________________________
Set goals.
I would like to do ___________________________________ By (date) ____________.
Slide 20:

This slide describes how individuals can impact care and improve the medical home on many different levels. For example, as consumers you can advocate for change within your child’s own medical home. Read through the slide and note the additional suggestions for what families/individuals and practices can do.

At the State and National level the development of public policy will be important to promote the medical home. The medical home “movement” is visible at the local, state and national level. Ask your state’s Department of Health and Human Services what they are doing to promote the Medical Home in your state.

### Examining Care at Multiple Levels

- **Family/Individual can:**
  - Ensure practice is accessible (wheelchairs, office hours, etc)
  - Create and use a care plan/summary

- **Practice can:**
  - Identify children and youth with special health care needs (CYSHCN), provide care coordination, learn from and teach families

- **State can**
  - Set standards of quality care, require them in contracts
  - Partner for change across multiple practices

- **Nation can:**
  - Promote policy changes
  - Influence Medicare, Medicaid, private insurance, large employers to endorse medical home.

### Tip

Families/Individuals can:
- Partner with the practice on behalf of children
- Raise questions about the practices’ access to care and services (e.g. appointments, type of visits, hours of operation)
- Encourage/ help with the completion and use of care plans
- Ask for the help of a care coordinator and thank the practice for this help.

Practices can:
- Develop methods to identify patients who need “extra-ordinary” care
- Dedicate time for care coordination
- Discuss with families the opportunities to improve care and communication

### Exercise Slide 20:

Review the American Academy of Pediatrics website to find out about national events [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org) or your state Department of Health and Human Services website.
Slide 21:

We hope you have developed ideas and possibilities that can improve your medical home. The next step is to spend time writing down what you would like to do next, in other words, create your own action plan.

Write down three actions/ideas that you can try or use at your child’s (or your) next appointment. Take about 3 – 5 minutes to complete. Share your ideas with your instructor or with others in your learning group (if applicable).

Action Planning

1) Brainstorm 3 actions/ideas that you can try or use at your child’s (or your) next appointment.
2) Share your ideas with the larger group

My Action Plan:
Slide 22:

If your understanding of the Medical Home is still unclear, ask your instructor for further assistance, and/or contact any of the resources listed on Slide 23. Share any additional thoughts or concerns with your instructor and/or other medical home resource people.

Please complete the brief evaluation in your handouts (if applicable). Return the completed evaluation to your instructor. If you would like more information, please complete the section at the bottom of the evaluation form.

The last slide has additional medical home contact information.

---

**Summing Up!**

- Questions?
- Additional thoughts?
- Please complete brief evaluation.
  Thank you!
Slide 23:
This is the final learning session slide. For more information feel free to contact the organizations listed below.

Contact us for Follow-Up

Center for Medical Home Improvement
Crotched Mountain Foundation
Concord Office:
18 Low Avenue STE 1, Concord NH 03301
603-228-8111
www.medicalhomeimprovement.org

Institute on Disability, UNH/UCED
10 West Edge Drive, Durham, NH 03824
aedillon@unh.edu 862-0793 or 862-4840

Family Voices
Concord, NH 03301
1-800-852-3345 ext 4525 (in state)
http://www.nhfv.org

Special Medical Services, NHDHHS/Title V, CSHCN Program
Concord, NH 03301
1-800-852-3345 ext 4488 or 603-271-4488

Funding has been provided by the Maternal and Child Health Bureau, Integrated Services Division, HRSA (Grant # H02MC02613) and NH Special Medical Services Bureau, HHS.

Notes:

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
Appendix A

DEFINITIONS OF COMMONLY USED TERMS
DEFINITIONS OF COMMONLY USED TERMS

Acute illness:
An acute illness is an illness or disease that comes on rapidly and is short in length (lasts only a couple weeks or so). Examples of acute illnesses are flu, colds, measles, mumps, etc.

Care coordination (CMHI):
Care and services performed in partnership with the patient, family, & caregiver by health professionals to:
1. Establish patient-centered community-based "Medical Homes" for patients with chronic health conditions and their families.
2. Facilitate timely access to the Primary Care Provider (PCP), services and resources.
3. Build bridges among patients and health, education, social services and employer; promotes continuity of care
4. Supply/provide access to referrals, information and education for patients and caregivers across systems.
5. Maximize effective, efficient, and innovative use of existing resources.

Care plan:
Care plans consist of three sections: 1) medical summary 2) action plan 3) emergency plan. It is a written document describing the medical needs of an individual. The care plan can include health history, diagnosis, medication, and contact information. A “medical home” care plan is written by the Primary Care Physician and/or health professional in partnership with the patient and/or family. Ideally, the original copy is kept at the practice and a copy is given to the individual/family. Thus, it is considered portable in which the individual/family can share with others as they deem applicable.

Children and youth with special health care needs (CYSHCN):
The United States Maternal and Child Health Bureau (USMCHB) definition of CYSHCNs to includes all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Chronic health condition: (children and youth with special health care needs)
The United States Maternal and Child Health Bureau definition includes all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Chronic condition management:
Involves explicit changes in the roles of providers and office staff aimed at improving:
- Access to needed services
- Communication with specialists, employers, and other resource supports, and
- Outcomes for patients, families, practices, employers and payers.
**Family-centered care:**
Family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care helps support the family’s relationship with the child’s health care providers and recognizes the importance of the family’s customs and values in the child’s care. (HRSA, US Maternal and Child Health Bureau, National Survey of Children with Special Health Care Needs Chartbook, 2005/2006)

**Health promotion:**
Health promotion is a commonly used term to define the different actions taken to improve the physical and mental well-being of children and youth and also to prevent illness. Examples of health promotion actions are childhood immunizations, health education in eating a balance diet, car seat safety, etc. Health promotion is provided by health care professionals (doctors, nurses, dentists, dieticians, therapists, etc.), community resources, government agencies, and parents.

**Medical Home:**
The American Academy of Pediatrics describes the medical home “as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care.” The Center for Medical Home Improvement defines the medical home “is a community-based primary care setting which provides and coordinates high quality, planned, patient/family-centered: health promotion (acute, preventive) and chronic condition management (© CMHI, 2006).”

**Medical home model:**
To copy or imitate the definition of medical home by applying it in practice.

**Medical homeness:**
To create the place where one goes for medical care that feels like home, e.g., familiar and comfortable.

**Medical summary:**
See definition of care plan. This term can be used synonymously with care plan.

**Office policies:**
Definite courses of action adopted for expediency; "the way we do things"; these are clearly articulated to and understood by all who work in the office environment.

**Patient-centered care:**
Patient-centered is providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions. (Institute of Medicine, 2001)

**Practice:**
The place, providers, and staff where the Primary Care Provider (PCP) offers medical care.

**Primary care provider (PCP):**
Physician or nurse practitioner who is considered the main provider of health care for the patient.
Appendix B

Companion Materials
<table>
<thead>
<tr>
<th>Patients and Families - Helping to Build Stronger Medical Homes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sample questions that may help you to partner with your Medical Home</strong></td>
</tr>
</tbody>
</table>

**Pick one or two that fit...**

<table>
<thead>
<tr>
<th>Access to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>★Family centered</td>
</tr>
<tr>
<td>★High quality</td>
</tr>
<tr>
<td>★Planned care &amp; care coordination</td>
</tr>
</tbody>
</table>

| 1. | Can my child’s chart be “flagged” to show that we are frequent users of the practice? (This helps the visit length to be right, and helps staff to better prepare) |
| 2. | How long is a typical visit at this practice? |
| 3. | How can we communicate with you; what is the best regular method? My family prefers _________________________type of communication. |
| 4. | Can we have a direct phone number for your key staff or care coordinator? (We’d like to avoid phone triage) |
| 5. | *(If needed)* can we access an exam room quickly or use the back door for access to a quiet room? How do we set that up? |
| 6. | *(If needed)* Do you have special equipment or special accommodations that we need? **Examples**: lift, latex free, wheelchair scale, automatic doors, etc. |
| 7. | Do you offer extended office hours (nights, weekends)? |
| 8. | How will the doctor or nurse on call access my child’s records? |

**Pick one or two that are important to you...**

<table>
<thead>
<tr>
<th>Provision of:</th>
</tr>
</thead>
<tbody>
<tr>
<td>★Family centered</td>
</tr>
<tr>
<td>★High quality</td>
</tr>
<tr>
<td>★Planned care, &amp;</td>
</tr>
<tr>
<td>★Care coordination</td>
</tr>
</tbody>
</table>

| 9. | Does each physician work primarily with one nurse? |
| 10. | Do you offer care coordination services? |
| 11. | Is there designated time for your staff to coordinate care? |
| 12. | Who can be my **care coordination** contact? |
| 13. | Do you develop and use care plans (written, shared information about medical needs, emergency steps, treatment plans, child & family strengths, and the numerous professionals involved)? |
| 14. | Are you able to work with us to develop a “portable” care plan? |
| 15. | Are you able to partner with us to learn about my child’s condition **and** help to advocate for him/her with others? |
| 16. | What supportive services are available? Specify________________________ (Examples you may need): behavioral health; nutrition; referral supports; and follow up; comprehensive care coordination; etc. |
| 17. | How are referrals to specialists managed in the office? |
| 18. | How is communication among you, specialists and us coordinated? (How can we help with this?) |
| 19. | Is it possible to schedule a visit with the physician - without our child/youth present? |
| 20. | Can you or someone come to the emergency room (ER) when we must go there? |
| 21. | Will my child’s information be accessible at the ER? |
| 22. | What hospital(s) are you affiliated with, or are you affiliated with the hospital we use? |

**You might ask about...**

| Outreach: Family & Community |

| 23. | How do you learn from your patients and families? Do you have any kind of family advisory group? How do you use family input? |
| 24. | How do you learn about and provide up to date resource guidance? Can I help? |
| 25. | In what ways does the practice learn about, communicate and collaborate with community schools and agencies? |

©CMHI, 4/28/09
# Sample Care Plan

<table>
<thead>
<tr>
<th>Date Completed</th>
<th>Date Revised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s Name</td>
<td>Nickname</td>
</tr>
<tr>
<td>DOB</td>
<td></td>
</tr>
<tr>
<td>Parent (Caregiver)</td>
<td>(Relationship)</td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Phone # (home)</td>
<td>Blocked? Y [ ] N [ ]</td>
</tr>
<tr>
<td>E-Mail</td>
<td></td>
</tr>
<tr>
<td>Emergency Contact</td>
<td>Phone</td>
</tr>
<tr>
<td>Health Insurance/Plan</td>
<td>Identification #</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnose(s): Primary:</th>
<th>Secondary:</th>
<th>Secondary:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Plan</td>
<td>Yes [ ]</td>
<td>Not Applicable [ ]</td>
</tr>
</tbody>
</table>

## Allergies

<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### MEDICATIONS:

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DOSE</th>
<th>FREQUENCY</th>
<th>MEDICATION</th>
<th>DOSE</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### SPECIALISTS:

<table>
<thead>
<tr>
<th>PROVIDER</th>
<th>HOSPITAL</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vital Sign (baselines):</th>
<th>Ht</th>
<th>Wt</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Problem List and recommended actions** (check all that apply, please explain in space below):

<table>
<thead>
<tr>
<th>Problem</th>
<th>Recommended Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
</tr>
<tr>
<td>Feed &amp; Swallowing</td>
<td></td>
</tr>
<tr>
<td>Hearing/Vision</td>
<td></td>
</tr>
<tr>
<td>Learning</td>
<td></td>
</tr>
<tr>
<td>Orthopedic/Musculoskeletal</td>
<td></td>
</tr>
<tr>
<td>Physical Anomalies</td>
<td></td>
</tr>
<tr>
<td>Sensory</td>
<td></td>
</tr>
<tr>
<td>Stamina/Fatigue</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

### TO BE AVOIDED:

- Medical Procedures:
- Activities:
- Foods:
PRIOR SURGERIES/PROCEDURES:

#1 Date
#2 Date
#3 Date

MOST RECENT LABS/DIAGNOSTICS (AS APPROPRIATE):

<table>
<thead>
<tr>
<th>TEST</th>
<th>DATE OF PROCEDURE</th>
<th>RESULT</th>
</tr>
</thead>
<tbody>
<tr>
<td>LABWORK (Specify)</td>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRUG LEVELS (Specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EEG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EKG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>X-Ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C-Spine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI/CT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

EQUIPMENT/APPLIANCES/ASSISTIVE TECHNOLOGY:

- Gastrostomy
- Adaptive Seating
- Wheelchair
- Tracheostomy
- Communication Device
- Orthotics
- Suctions
- Monitors: Crutches
- Nebulizer
- Apnea
- O2
- Walker
- Other
- Cardiac
- Glucose
- Other

SCHOOL/COMMUNITY INFORMATION:

<table>
<thead>
<tr>
<th>AGENCY/SCHOOL/CHILD CARE</th>
<th>CONTACT INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

FAMILY INFORMATION:

SPECIAL CIRCUMSTANCES/COMMENT/WHAT YOU WOULD LIKE US TO KNOW:

Parent/Caregiver Signature Date

Primary Care Provider Signature Print Name Contact Info Date

Care Coordinator Signature Print Name Contact Info Date
Extra-Ordinary Care: Improving Your Medical Home

WORKSHOP EVALUATION

What I liked best about this presentation:

How I think I’ll use the Information I learned today:

Something new I learned:

What I still need to learn:

This is what I suggest for improving this workshop.

Optional… if you would like more information please complete below.
Name ____________________________________________
Phone # ____________________________ or Email ____________________________
Your request: _______________________________________________________

Thank you!

This is an activity of the Center for Medical Home Improvement (www.medicalhomeimprovement.org) with program partner NH Family Voices. Funding is from NH HHS - Special Medical Services.