



**Medical Home
Education Workgroup**

To participate, please call:
1/866-489-0573 (toll free)
At the prompt, enter
4545164

Agenda

Friday, March 14th 2008

11:00 – 12:30pm Central

12:00 – 1:30pm Eastern

1. Roll Call/Introductions
2. Review of Previous Meetings – Where are we, how did we get here, and where are we going?
 - a. Region 4 Overview
 - b. Participant roles
 - c. WG Charge and Year One Plan
 - d. Group Focus: Parent Education Materials
 - e. Education Plan Template (Handout 1)
3. Review of Materials (Handout 2)
4. Educational Objectives (Back to Handout 1)
5. Visiting Professorship
 - a. An application has been submitted
 - b. Region 4 requested AAP to provide technical assistance on developing effective strategies to increase family awareness and involvement in medical home
6. Parent Meeting Week of May 19th 2008
 - a. Two day meeting in Lansing, Michigan
 - b. Tentative agenda – Brainstorming session and Leadership training
 - c. Travel, accommodation, and reimbursement information

Materials:

Agenda and Work plan

Education Plan Template (Handout 1)

Review of Materials (Handout 2)

Medical Home Education Work plan

Goal: Educate primary care providers, specialists, and families about the importance of providing a medical home for children with heritable disorders.



A. Year One Goal: Identify, review and select existing initiatives and materials to educate Region 4 families and providers			
Objective	Who	What	When
1. Identify existing training initiatives and materials	MPHI	Conduct Internet research	December 2007
	Group	Provide input re: state initiatives	
	Group	Provide existing State materials	January 2008
	MPHI	Compile and distribute list of materials/initiatives	
	Group	Discuss existing materials	
2. Develop criteria for assessing materials (quality, cost, feasibility, adaptability)	Co-chairs/MPHI	Research assessment tools	February 2008
	Group	Brainstorm assessment criteria	
	Co-chairs/MPHI	Develop/modify assessment tool	March 2008
	Group	Review and finalize assessment tool	
3. Review training initiatives/materials based on established criteria	Group	Assess materials using assessment tool	April 2008
	Co-chairs/MPHI	Compile/summarize reviews	
	Group	Refine list of materials and training initiatives	
4. Identify the best methods to disseminate information (on-line course, face-to-face training, individual consultation, etc.)	Co-chairs/MPHI	Literature review (training and dissemination)	May 2008
	Group	Review literature summary	
	Group	Determine best methods for each target group	
	Co-chairs/MPHI	Summarize group recommendations	
5. Develop Region 4 education plan	Co-chairs/MPHI	Draft education plan including materials/methods	June 2008
	Group	Provide input on education plan	
	Group/co-chairs	Adopt finalized education plan	
B. Adapt medical home materials to address the needs of children with heritable disorders in Region 4			Years 2-5
C. Share adapted materials with region 4 partners, other regions, and national audiences			
D. Provide educational opportunities in Region 4			

Goal: Educate families about the importance of medical homes for children with heritable disorders

- Revise medical home materials to address heritable disorders
- Distribute materials and/or provide training opportunities in each state

	Example(s):
<p>1. Educational Objectives</p> <p>What do parents want to know about medical home? What content will we cover? What resources or tools are important?</p>	<ol style="list-style-type: none"> 1. <i>What is a medical home?</i> 2. <i>What are the benefits of a medical home?</i> 3. <i>What can I expect from a medical home?</i> 4. <i>How do I know if I have a medical home (checklists, tools, etc.)?</i> 5. <i>What is a parent/professional partnership?</i> 6. <i>What is my role as a parent? How can I build a partnership?</i> 7. <i>How do I communicate effectively with my physician?</i> 8. <i>How do I work with my physician to improve care for my child?</i> 9. <i>How do I effectively advocate for my child?</i> 10. <i>Where do I go to find parent support resources?</i> 11. <i>How do I find a physician that gets it (referrals, etc.)?</i> 12. <i>How can parents monitor their child's health (record keeping, forms, creating care notebooks, etc.)?</i> 13. <i>How can I talk to my physician about MH/encourage my Dr. to start a MH (existing initiatives, becoming a parent partner)?</i> 14. <i>What is care coordination/what is a care coordination plan?</i>
<p>2. Target Group</p> <p>Who is the intended audience?</p>	<p><i>Families of children with genetic conditions in Region 4 States</i></p>
<p>3. Educational Materials</p> <p>What written materials will be used to educate parents?</p>	<p><i>Brochures (Title)</i> <i>Website (Title)</i> <i>Poster (Title)</i> <i>PowerPoint Presentations (Title)</i></p>
<p>4. Point in Time</p> <p>At what time will parents benefit most?</p>	<p><i>At time of diagnosis?</i> <i>When meeting with a genetic counselor?</i> <i>When they contact an advocacy organization?</i></p>
<p>5. Method of Dissemination</p> <p>How will the materials get to our target group?</p>	<p><i>Web-based</i> <i>Email list</i> <i>Conferences</i></p>
<p>6. Training Methods</p> <p>What training methods will be employed?</p>	<p><i>One-on-one (parent mentoring, nurse coaching)</i> <i>Group presentation</i> <i>Online Training Module</i></p>
<p>7. Partnerships</p> <p>What other groups will we need work with in order to accomplish our goals?</p>	<p><i>Parent advocacy groups</i> <i>Genetics organizations</i> <i>Physician groups</i></p>
<p>8. Evaluation Strategies</p> <p>How will we determine if our educational objectives were met?</p>	<p><i>Surveys</i> <i>Website hits</i> <i>CEU's</i></p>

Title	
1. A Family-Professional Partnership	Page 4
2. Choosing a Pediatrician	
3. Helping Children with Special Healthcare Needs	
4. What Should Medical Facilities Look Like?	
5. Medical Home Series 2007 (Articles 1-5)	Page 4
6. A Guide for Parent and Practice "Partners" Working to Build Medical Homes for CSHCN.	Targets providers working with parent partners to implement medical home changes
7. A NEW WAY...A BETTER WAY. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs	State Specific Brochure See Page 2
8. Family Brochure: Every Child Deserves a Medical Home	State Specific Brochure See Page 2
9. Medical Home: Families and Providers Working Together	State Specific Brochure See Page 2
10. What is a Medical Home: How Can it Help Your Child with Special Needs	State Specific Brochure See Page 2
11. A Medical Home: Consistent, Knowledgeable, and Comforting Health Care	Not able to locate. May no longer be available.
12. I want my Medical Home: A parent perspective on what a Medical Home means to families.	Presentation: On hold
13. Making Health Care Work For You: Medical Home 101	Presentation: On hold
14. Family Survey of Medical Home Outcomes	Very long and detailed survey for use by providers to survey parents
15. Texas Medical Home Toolkit for Families	See Page 3
16. AAP Pediatrician Referral Service	See Page 3
17. Primer on the Illinois Medical Home Model for Families	See Page 3
18. Medical Home: A Guide for Minnesota Parents	State Specific Brochure See Page 2
19. Working with Doctors: A Parent's guide to navigating the health system.	See Page 3
20. Special Connections Newsletter	This edition is out of date; mostly relevant to families involved in the Minnesota project
21. Family Guide to Michigan's Children's Special Health Care Services Program	See Page 3
22. Introducing Families to the Illinois Medical Home Model	This is an older version of number 8.

Title	Date	Summary of information/topics covered	Quality	Usability	Comments
A NEW WAY...A BETTER WAY. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs (#7) New England SERVE	No date	Basic overview including definitions, what to expect and how to get more info. Topics: <ul style="list-style-type: none"> • How to find a Dr. who gets it • How to get more support from current physician • Where to go to learn more about medical home partnerships in Mass. • What should I expect from my child's medical home? • What is a medical home? 	High	Middle	+Straightforward, no jargon +Specific practical tips for MH in the office +Includes checklist for assessing medical home +Comprehensive - Print is small - May have too much information – more than a few key points, readability
Family Brochure: Every Child Deserves a Medical Home (#8) Illinois	2/08	<ul style="list-style-type: none"> • What is a medical home? • Tips to make appointments work for you • Goals of medical home • Family/professional partnership 	High	Mid - High	+Clear and simple +Includes parent and physician quotes +I like in particular the check mark tips +Good use of white space, not too much text - Mentions care plan but does not define - Doesn't explain how to get a med home - Very basic overview - short brochure
Medical Home: Families and Providers Working Together (#9) Washington State	3/03	<ul style="list-style-type: none"> • What is a medical home • Benefits of a medical home • Tips for building medical home partnership • Family Support Programs in Wash • Washington State Website topics 	Mid	Mid- High	+Format is very clear +I like the color scheme and layout w bullets and simplified points + Well organized, simplified but with enough detail + Benefits listed, seems family oriented - No contact info for questions about brochure besides website
What is a Medical Home: How Can it Help Your Child with Special Needs (#10) South Carolina	No date	<ul style="list-style-type: none"> • What is a medical home? • Working with your physician to improve care for your child • Why is a medical home important? • Medical home initiatives in S. Carolina • Opportunity to become an advocate 	High	Mid	+Become an advocate section includes a tear off and request for family and provider brochures -Print is very small; Very brief
Medical Home: A Guide for Minnesota Parents (#18) Minnesota	No date	<ul style="list-style-type: none"> • What is a family-centered partnership? • What is a med home? • What can parents do to create a med home for their child? • What defines CSHCN? • Provides web resources 	Mid	Mid- high	+Includes parent quote and practical ideas +Format is clear and simple -Seems like they tried to fit a little bit too much info in a small space -Statement that pediatric care not designed for kids w/special needs should link back to med home

Type of Resource: Varies

Purpose: To inform/offer tools and guidance

Depth: Beyond an overview

Title	Date	Summary of information/topics covered	Quality	Usability	Comments
<p>Texas Medical Home Toolkit for Families (#15)</p> <p>Texas parent to parent Texas medical home WG Texas Health Dept./CSHCN</p> <p>Toolkit</p>	<p>Not listed</p>	<ul style="list-style-type: none"> • What is a medical home? • What are families looking for in a medical home? • Medical home checklist for parents to assess provider? • Existing med home initiatives • How to reach physician training programs • How to become a parent partner • Links to website tools 	<p>High</p>	<p>Middle</p>	<p>+ I like Intro - letter written by a parent + I really liked the Texas Medical Home Tool box. + links are still up and running -I liked the checklist - evaluation at the end is a good idea - Geared toward parents interested in system level work – may not be for every parent -too many links, overwhelming - not for parents only -PDF version is very wordy – key points are lost and not enough white space or graphics</p>
<p>AAP Pediatrician Referral Service (#16)</p>	<p>Not listed</p>	<p>Resource is a website – phone and address are provided under “contact us”</p>	<p>N/A</p>	<p>High</p>	<p>+ helpful for searching for specialists in their area + several different ways to do search +Easy to use website</p>
<p>Primer on the Illinois Medical home Model for Parents (#17)</p>	<p>Up to date</p>	<ul style="list-style-type: none"> • What is a medical home • What is family-professional partnership • How can Illinois DSCC support parents • What is a care coordination plan? • How to get involved in med home quality improvement team • Elements of “Medical Homeness” • Med home web-based resources 	<p>Mid-High</p>	<p>Mid-High</p>	<p>+Very detailed; seems to cover the right topics +Very friendly conversational tone with examples to illustrate points +Mostly overview but provides some in depth info +Number of resources and links listed +Filled with great info - Hard to look at – too much info on one page - Difficult to read due to format - key points do not jump out - not enough bullets, white space, graphics, etc. -May be hard if no computer access</p>
<p>Working with Doctors: A Parent's guide to navigating the health system. (#19)</p> <p>Book – hardcopy only</p> <p>PACER center (Parent Advocacy)</p>	<p>2003</p>	<ul style="list-style-type: none"> • How to be an advocate for your child • Communicating with Dr.'s –detailed • Choosing a physician – step by step • Medical Record keeping ideas • Examples of emergency/other forms and where to find them online • Info about PACER Center 	<p>High</p>	<p>Hlgh</p>	<p>+ I liked the forward and dedication +Describes medical home from a parent point of view with no jargon, no buzz words +info is very clear, organized, uncluttered, easy to read, key points are clear -helpful in beginning stages of advocacy -Too much white space - Layout lacks effectiveness -8 1/2 X 11 would be better size -a few changes in font and page layout would help</p>
<p>Family Guide to Michigan's Children's Special Health Care Services Program (#21)</p> <p>Manual</p>	<p>2006</p>	<p>This is a comprehensive guide to Children's Special Health Care Services in Michigan. It also includes general info including:</p> <ul style="list-style-type: none"> • What is a medical home? • Building health partnerships • Glossary of commonly used med terms • Reproducible forms • How to create a care notebook 	<p>High</p>	<p>Hlgh</p>	<p>+I really like this book, clear and concise, lots of resources, useful information, key points jump out +Info about creating a care notebook is fantastic +Glossary of commonly used medical terms is helpful +Love the use of internet sources and reproducibles +Medical home explanation is very good -Much of the info is Michigan only</p>

Type of Resource: Exceptional Parent Articles Purpose: To inform/offer tools and guidance Depth: Beyond an overview

Title	Date	Summary of information/topics covered	Quality	Usability	Comments
A Family-Professional Partnership (#1) Exceptional parent magazine article	2000	<ul style="list-style-type: none"> Three-part communication log/tool for parents to use for med professionals, schools, caregivers, etc. 	Mid	Low-Mid	+ includes resources of how parents can monitor their child's health - seemed like too much information, certainly not a resource for every parent
Choosing a Pediatrician (#2) Exceptional parent magazine article	2000	<ul style="list-style-type: none"> How to choose a pediatrician Includes a rating form to use when choosing a health care provider 	Mid	Mid	+includes a survey tool to use to rate the quality of your physician -few details about how to choose a pediatrician, mostly the rating tool only
Helping Children with Special Healthcare Needs (#3) Exceptional parent magazine article	2000	<ul style="list-style-type: none"> What is a Medical Home Benefits of a medical home Existing Medical Home initiatives 	Mid	Mid	+Defines Medical Home in some detail -The writing includes somewhat complicated language -seemed like not enough information, just an overview
What Should Medical Facilities Look Like? (#4) Exceptional parent magazine article	2000	<ul style="list-style-type: none"> Describes the optimal design and architecture of a medical facility Describes a rating tool that was used to evaluate the medical offices environment 	Mid	Mid	+Highlights the importance of design and architecture in a medical office -The writing includes some complicated language -Overview of a research study, may not be practical information for parents

Type of Resource: Case Study/Family History Purpose: To inform using one family's experience Depth: Beyond an overview

Title	Date	Summary of topics/information covered	Quality	Usability	Comments
Medical Home Series 2007 (#5) Articles 1-6	2007-08	Describes MH including how it works, details, benefits through a case study/history of a family.	Mid-High	Mid-High	+Parents may find the story interesting and learn something from the case history -Not a lot of practical information