



Agenda

Friday, April 11th 2008
11:00 – 12:30pm Central
12:00 – 1:30pm Eastern

1. Roll Call/Introductions
2. Review of Previous Meetings
 - a. WG Charge and Year One Plan
 - b. Group Focus: Parent Education Materials
 - c. Revised List of Materials (Handout 1)
 - i. Brochures (Handout 2)
 - ii. Comprehensive resources
 - d. Educational Objectives

Objective 1: Medical Home

*What is a medical home?
What are the benefits of a medical home?
What can I expect from a medical home?*

Objective 2: Working with physicians

*What is a parent/professional partnership?
What is my role as a parent?
How do I communicate effectively with my physician?*

Objective 3: Care coordination

*What is care coordination?
What is a care coordination plan?*

Objective 4: Parent support resources

Objective 5: Reproducible forms, tools, checklists (record keeping, etc.)

3. Comprehensive Resources and Educational Objectives (Handout 3)

How well does each resource meet our educational objectives?

4. Parent Meeting May 19th and 20th
 - a. Update and Reminder
 - b. Questions
5. Regional Meeting September 16th and 17th
 - a. Update and Reminder
 - b. Questions

6. Next Steps

Materials:

Agenda and Work plan
Revised List of Parent Materials (Handout 1)
State Specific Brochures (Handout 2)
Comprehensive Resources (Handout 3)




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			

Handout 1: Medical Home Education (Target Group: Families)

Title	Format	Review Notes
1. A Family-Professional Partnership	Magazine Articles	Supplementary Material
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)	Medical Home Series	Supplementary Material
6. A Guide for Parent and Practice "Partners" Working to Build Medical Homes for CSHCN.	Booklet	Does not target parents
7. A NEW WAY...A BETTER WAY. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs	Brochure	State specific brochure
8. Family Brochure: Every Child Deserves a Medical Home	Brochure	State specific brochure
9. Medical Home: Families and Providers Working Together	Brochure	State specific brochure
10. What is a Medical Home: How Can it Help Your Child with Special Needs	Brochure	State specific brochure
11. A Medical Home: Consistent, Knowledgeable, and Comforting Health Care	Fact Sheet	Not able to locate.
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	Survey	Does not target parents
15. Texas Medical Home Toolkit for Families	Toolkit PDF or Word	Overwhelming amount of information; targets parents interested in becoming medical home advocates
16. AAP Pediatrician Referral Service	Web-based	Supplementary Material
17. Primer on the Illinois Medical Home Model for Families	Website	Comprehensive; positive reviews
18. Medical Home: A Guide for Minnesota Parents	 Brochure-MH4.pdf Brochure	State specific brochure
19. Working with Doctors: A Parent's guide to navigating the health system.	Hard Copy Book	Comprehensive; positive reviews
20. Special Connections Newsletter	 mdhmspec05f1.pdf	Mostly relevant to those participating in the Minnesota project.
21. Family Guide to Michigan's Children's Special Health Care Services Program http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-15087--,00.html	Booklet	Comprehensive; positive reviews
22. Introducing Families to the Illinois Medical Home Model	 Med Home for IL Families 4016[1].pdf	Older version of #8.

State Specific Brochures – Provide an Overview (Handout 2)					
	Medical Home	Working with Physicians	Care Coordination	Parent support resources	Forms and tools
New England SERVE	X	X		X	X (checklist)
Illinois	X	X		X	X (checklist)
Washington State	X	X		X	
South Carolina	X	X		X	
Minnesota	X	X		X	

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

Title	Date	Summary of information/topics covered	Quality	Usability	Comments
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

Comprehensive Resources – Handout 3

Educational Objectives					
	Medical Home What is a medical home? What are the benefits? What can I expect?	Working with Physicians What is a parent/professional partnership? What is my role? How do I communicate effectively with my physician?	Care Coordination What is care coordination? What is a care coordination plan?	Parent support resources Where do I go to find parent support resources?	Forms Provides (reproducible) forms and other practical tools such as checklists to assist parents with record keeping etc.
Primer on the Illinois Medical Home Model for Families					
Working with Doctors: A Parent's guide to navigating the health system.					
Family Guide to Michigan's Children's Special Health Care Services Program					

Title	Date	Summary of information/topics covered	Quality	Usability	Comments
Primer on the Illinois Medical home Model for Parents (#17)	Up to date	<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 	Mid-High	Mid-High	+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
Working with Doctors: A Parent's guide to navigating the health system. (#19) Book – hardcopy only PACER center (Parent Advocacy)	2003	<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 	High	High	+ 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 -May put some people off because it looks like a kids book
Family Guide to Michigan's Children's Special Health Care Services Program (#21) Manual	2006	This is a comprehensive guide to Children's Special Health Care Services in Michigan. It also includes general info including: <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 	High	High	+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