





Region 4 Genetics Collaborative Base Funding Logic Model

Assumptions

1. Collaboration among stakeholder groups, Region 4 states, across regions, and with national partners will improve access to genetic services, expertise, and information in the context of the medical home for children with heritable disorders and their families

2. Effective follow-up for children with heritable disorders provides “just in time information” to the child’s family and medical home. This includes children identified through newborn screening, early hearing detection, birth defect registries, CSHCN, and early intervention programs.

3-7. Children with heritable disorders who have access to genetic services, expertise and information within the context of a medical home will have better health outcomes and quality of life. *In order to successfully establish medical homes for children with heritable disorders the following conditions must exist:*

3. Families and providers must be aware of how the medical home model improves care and outcomes for children with heritable disorders

4. Care coordination must be provided

4. Families, genetic specialists and primary care providers must communicate effectively

4. Care plans must be easily accessible by providers and families

Goals & Strategies

Goal 1: Facilitate collaboration within Region 4, with national partners and across regional collaboratives

- Solicit input and direction from stakeholders
- Establish/expand workgroups
- Facilitate ongoing communication
- Support parent participation
- Facilitate collaboration across regions

Goal 2: Develop & distribute follow-up protocols for population-based identification of children with heritable disorders

- Conclude efforts of Short Term NBS Workgroup
- Collaborate with Indiana NBS Follow-up project
- Expand Follow-up Workgroup to include: EHDI, birth defects registry, early intervention
- Develop and disseminate follow-up protocols

Goal 3: Educate primary care providers, specialists & families about the importance of medical homes for children with heritable disorders

- Revise medical home materials to address heritable disorders
- Provide educational opportunities in each state
- Explore educating medical residents & nurses

Goal 4: Promote care coordination for children with heritable disorders

- Promote care plans for children with heritable disorders
- Create Learning Consortia to identify & resolve barriers to effective communication
- Implement the use of Emergency Information Forms (EIF)
- Revise EIF to facilitate electronic sharing of care plans

Outcomes

Goal 1

- Improve collaboration across stakeholder groups; among Region 4 states; with national partners & with other regions

Goal 2

- Improve follow-up practices for children with heritable disorders who are identified through: NBS, EHDI, birth defect registries, early intervention

Goal 3

- Increase # of parents and providers who understand how the medical home improves care and child outcomes
- Increase the number of parents advocating for their children to have a medical home
- Increase the # of children with heritable disorders being served by a medical home

Goal 4

- Increase access to care plans that are specific to heritable disorders
- Improve communication among families, specialists and primary care providers
- Improve quality of care for children with heritable disorders
- Increase access to emergency care plans for children with heritable disorders
- Increase the # of children with heritable disorders who have an accessible care plan



Assumptions

In order to successfully establish medical homes... the following conditions must exist (continued):

5. Reimbursement must be available for services integral to the medical home model, such as care coordination.

6. Parents and primary care providers must have easy access to information about specific disorders

7. Access to genetic expertise must be available, especially in underserved (rural) areas

8. Children with heritable disorders who are transitioning to adulthood will have better outcomes if:

- Families and providers are aware of the importance of a transition plan
- The transition plan is developed by the patient, the family and all care providers

Goals and Strategies

Goal 5: Address reimbursement issues that are barriers to quality care

- Identify barriers to reimbursement for care coordination; identify and implement strategies to resolve barriers
- Identify barriers to reimbursement for medical foods & formulas; identify and distribute successful strategies to resolve barriers

Goal 6: Provide access to genetic information, resources and disease management guidelines in the context of a medical home

- Promote the use of accurate disorder-specific resources
- Develop disorder-specific electronic grand rounds

Goal 7. Facilitate access to genetic expertise for underserved populations

- Promote links between genetic specialists and rural health service & communication systems
- Explore practice models to assist the limited number of genetic specialists in maximizing use of their time

Goal 8. Identify and promote effective models addressing transition to adult services for youth with heritable disorders

- Promote the use of individual transition plans
- Promote the use of strategies to develop and implement a systems approach to supporting transition
- Participate in the National Transition Workgroup
- Address regional needs identified through data analyzed by Healthy & Ready to Work

Outcomes

Goal 5

- Reduce barriers to reimbursement for care coordination
- Increase # of providers who understand how to overcome barriers to reimbursement for care coordination
- Increase knowledge of families and providers about strategies to overcome barriers to reimbursement for medical foods & formulas

Goal 6

- Improve access to genetic information within the context of the medical home

Goal 7

- Improve access to genetic expertise for underserved populations
- Maximize time of genetic specialists and genetic counselors so expertise is ultimately available to more families

Goal 8

- Improve access to transition plans & protocols for families & providers
- Increase skills of children & families to prepare for transition
- Increase the number of children transitioning to adult services who have a transition plan

Handout 3: Workplan



Medical Home Education Workgroup: Year One Plan

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

A. 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	
	MPHI	Compile and distribute list of materials/initiatives	January 2008
	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 - best education methods	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			



Medical Home Education Workgroup

Medical Home Materials and Initiatives

National Training Curriculum

- ***AAP: The National Center for Medical Home Improvement: Every Child Deserves a Medical Home Training Curriculum***

Training Materials are available online at AAP National Center of Medical Initiatives for Children with Special Needs:

<http://www.medicalhomeinfo.org/training/materials.html>

Medical Home Implementation Resources

- ***Crotched Mountain: Center for Medical Home Improvement (CMHI): Building a Medical Home: Improvement Strategies in Primary Care for Children with Special Health Care Needs (Medical Home Improvement Kit)***

The toolkit is available online at: <http://www.medicalhomeimprovement.org/mhik.htm>

- ***Wisconsin Medical Home Toolkit***

[Wisconsin Medical Home Toolkit](#) available online!



Handout 4: Materials and Initiatives

Educational Materials

- ***Primer on the Illinois Medical Home Model for Physicians***

[Primer on the Illinois Medical Home Model for Physicians](#)

- ***Primer on the Illinois Medical Home Model for Families***

[Primer on the Illinois Medical Home Model for Families](#)

- ***Medical Home Project Learning Session II, March 10, 2007: Presentations (video-taped)***

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*Windows Media Player is necessary to view the presentations at the following link:

<http://video.google.com/videosearch?q=%22medical+home%22>

- ***Enhancing Collaboration Between Primary and Subspecialty Care Providers for Children and Youth With Special Health Care Needs*** [Workbook](#) 

- ***Innovative Approaches for Improving Referral, Consultation, and Shared Management in Primary and Specialty Pediatric Care***

[Promising Approaches for Improving the Interface between Primary and Specialty Pediatric Care](#)

Handout 4: Materials and Initiatives

Educational Initiatives – National

- NICHQ Medical Home Learning Collaboratives The National Initiative for Children's Healthcare Quality, Inc. (NICHQ) with support from the US Maternal and Child Health Bureau ran two National Medical Home Learning Collaboratives. These fifteen-month programs helped facilitate the improvement of care for the growing population of children and youth with special health care needs <http://www.medicalhomeinfo.org/model/MHLC.html>
- **Medical Home Mentorship Program** Guidance, resources, and networking opportunities for individuals, communities and states to assist them in achieving increased access to medical homes. <http://www.medicalhomeinfo.org/model/index.html>

Educational Initiatives – State

- **Illinois Educational Outreach Includes Medical Grand Rounds and CATCH Meetings**
- **Illinois Physician Outreach**
- **Illinois Pediatric Specialists Available for Consultation to Assist Primary Care Physicians Managing Care for CSHCN**

Information about Illinois Initiatives can be found at: <http://www.medicalhomeinfo.org/states/state/illinois.html>

- **Wisconsin Medical Home Special Needs Rotation**

[Presentation](#) 

Marketing Materials

Outreach and marketing materials to promote medical homes for children with special needs at AAP: The National Center for Medical Home Initiatives for Children with Special Needs. Materials can be adapted.

<http://www.medicalhomeinfo.org/tools/Marketing.html>