

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, CSHCN, 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