



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>Medical Home What do parents want to know about medical home? What content will we cover? What resources or tools are important?</p>	<p>1. Medical Home</p> <p>a. <i>What is a medical home?</i></p> <p>b. <i>What are the benefits of a medical home?</i></p> <p>c. <i>What can I expect from a medical home?</i></p> <p>2. Working with physicians</p> <p>a. <i>What is a parent/professional partnership?</i></p> <p>b. <i>What is my role as a parent?</i></p> <p>c. <i>How do I communicate effectively with my physician?</i></p> <p>3. Care coordination</p> <p>a. <i>What is care coordination?</i></p> <p>b. <i>What is a care coordination plan?</i></p> <p>4. Parent support resources</p> <p>5. Reproducible forms, tools, checklists (record keeping, etc.)</p>
<p>Region 4 & Heritable Disorders What do parents want to know about genetics/genetic conditions? What state specific information will we cover?</p>	<p><i>Region 4 Website</i> <i>FAQ's about Genetics</i> <i>Newborn Screening Fact Sheets</i> <i>Region 4 Specialist Map</i></p>
<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>Parents need to have everything at time of diagnosis</i> <i>Information should be made available on an ongoing basis so that parents can access it as they need it</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>	