

**Advisory Board Meeting
Wednesday, September 16, 2009—5:00-8:30 pm
Chicot Room (Level 2)**

Notes

Members: Barb Schweitzer (ND), Leslie Himstedt (AR), Majed Dasouki (KS), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Jackie Whitfield (AR), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Holly Johnson (AR), Larry Weatherford (OK), Brad Schaefer (AR), and Sharon Vaz (OK) **HRCC:** John Mulvihill (OK), Lori Williamson (OK) **Guests:** Ann Chou, Barb Jackson, Jill Shuger, Alaina Harris, Mary Ann Coffman, Kathy Harris, and Gloria Weissman

Agenda Item	Discussion	Action
<p>Mission & Vision Statements (Kim Piper & Julie Miller)</p>	<p>Problem/Concern: Citizens Council on Healthcare is using the Heartland Vision Statement as support for their case against the storage of newborn screening dried blood spots cards without parents consent.</p> <p>Piper and Miller provided examples of statements that organizations use to depict their values and purpose.</p> <ul style="list-style-type: none"> • Mission – the collaborative promotes & improves... • Vision – picture of service or inspiration for organization in the future; should be brief, include 4 goals of the Heartland • Giving Principle – direct the organization; a foundation • Code of Ethics – standards, values, rules <p>Issues for us to consider when revising our mission/vision statement:</p> <p>NBS Saves Lives Act HRSA Guidance Access Medical Home Public Health ACHDNC statements Overarching Principles in NBS Promoting Collaboration</p>	<p>Ad hoc committee to revise mission statement</p> <p>Subcommittee members: Leslie, Amy Brower, Sharon Vaz, Julie Miller, Sharmini Rogers</p> <p>Present Draft on conference call in October</p>

<p><i>Working Together</i> a profile of collaboration</p>	<p>Dr. Jackson provided a written (raw data) and oral summary of the <i>Working Together</i> survey. Overall, survey results indicated that the Heartland Advisory Board works well together.</p> <p>Areas assessed were:</p> <ul style="list-style-type: none"> • <i>Context</i>: Is the timing right to address the issues? • <i>Structure of Collaboration</i>: Are the necessary structures in place to support effective collaboration? • <i>Members</i>: Do the members' actions facilitate collaboration? • <i>Collaborative Process</i>: Do the meeting processes promote effective collaboration? • <i>Results</i>: Are there methods to monitor progress and address ways to improve outcomes? <p>Areas considered for improvement:</p> <ul style="list-style-type: none"> • Group has agreed on what decisions will be made by the group • Work to more clearly define roles for group members • Identify strategies to support balancing good for the home programs vs. the Collaborative • Need to identify strategies that can support individuals to devote effort to achieve RCs goals when they have responsibilities to home organization • Need to reflect on how group is working together • Enhance the process for measuring progress towards goals and celebrate successes <p>Coordinating Center team and consultants were excused while Advisory Board members discussed these areas.</p>	<p>Action 1: Determine how and what decisions will be made by the group.</p> <ul style="list-style-type: none"> • Develop a charter that outlines the decision making process including: <ul style="list-style-type: none"> • Scope (e.g., allocation of money resources/other, programmatic) • Roles (e.g., chair or vice chair structure) • Voting procedures (e.g., when needed) • Make up committees and how those are determined as well as their work scope • Address issues around how to respond to rapid response demands • Is there a quorum needed for business? • How do collaborative members outside of the advisory board (e.g., the general member or subgroup member) contribute ideas/suggestions to be addressed by the advisory board? <p>Timeline: A subgroup including Riske, Schaefer, and Williamson will develop a draft document and present to the Advisory board in December or the January Advisory Board conference call.</p>
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<p><i>Working Together</i> a profile of collaboration (continued)</p>	<p>Then, all participated in prioritizing the areas for improvement.</p> <p>The top three were selected:</p> <ul style="list-style-type: none"> • Determine how and what decisions will be made by the group. • Need to streamline methods to address new issues or changes in national policy or emphasis – rapid response strategy. • The scope of the collaborative is rather large, needs to have a discussion to determine how broad or narrow the scope should be. Secondly, based on the scope, identify ways to help the state coordinators not feel as overwhelmed with all the requests and activities that are going on. 	<p>Action 2: Determining the scope of the work of the Heartland Collaboration</p> <p>The broadness of the Heartland work scope will be discussed in light of the proposed mission and statements. At that time a work plan will be determined.</p> <p>Timeline: The advisory board will discuss and develop an action plan at the October Advisory Board meeting.</p>
<p>Open Mic Q&A</p>	<p>Q: When do new board members come on? Lori: New members-board will start in January (calendar year) Suggestion: Provide job description for being a board member</p> <p>Dasouki announced that a representative of the Batten Disease Foundation is raising money for a laboratory that would for screen for 500 autosomal recessive disorders.</p>	<p>Include advisory board member job description in charter.</p>