

**Care Coordination Workgroup Regional Meeting Session ~ Notes**  
**Friday, April 16<sup>th</sup>, 2010 ~ 12 pm ET**

Co-Leads: <b>Jennifer Arveson; Kathy Wood</b>	Facilitator: <b>Sally J. Hiner, Region 4 Genetics Collaborative Senior Project Coordinator</b>
<b>Participating:</b> Linda Drawhorn, IL; Kelly Jackson, Anne Weaver, KY; Lenee Simon, HRSA; Andy LaPrad, Beth Tarini, MI; Jen Arveson, MN; Sarah Wedepohl, R4.	
<b>Meeting Goals:</b> <b>Workgroup will consider input from Parent Partners Care Coordination Survey and Parent Meeting discussion</b> <b>Workgroup Identify next steps</b>	

Item	Discussion/Notes	Recommendation/Action	Follow up (who/when)
I. Welcome, Introductions and Meeting Overview – Wood/Arveson			
A. Roll Call			
II. Updates – Arveson/Wedepohl			
A. Parent Survey and Discussion Highlights	<p><b>SURVEY:</b> A survey of parents prior to the meeting was conducted to find out more about the care plans that parents have for their children. Seven parents responded to the survey. Parents reported that the top 4 providers involved in their plans are special education teachers, specialists, PCPs, and general education providers. Most of the care plans include details about disorder specific care, emergency health care, general medical care and education. All parents reported being given copies of their child’s care plans. Most parents also report that their care plans have been very useful to their families.</p> <p><b>DISCUSSION:</b> Eleven parents participated in the discussion. The goal of the meeting was to gather more information about how families utilize care plans and their opinions of care coordination and care coordination tools. Parents stated that they have a variety of care coordinating needs—some parents have somewhat seamless coordination of care between doctors/specialists (i.e., specialists communicate well with PCP through letters, or all doctors are in the same large university system with built-in communication). Other parents struggle with coordinating their children’s care (i.e., gaps in communication between specialists and other entities such as school) and would appreciate more tools. Parents would like to see: A list of what types of care coordination tools and care plans are recommended; Web access to care plans (possibly using a tool such as MEMSCIS that is available anywhere at anytime); Tips for parents to better understand care coordination (like thinking about transition issues); and Tips for using AAP “Build your own Care Notebook” website (which many parents found intriguing). Bob Cook shared Illinois’ Title V Waiver program Care Plan. This care plan is used for all children in the program and is updated at every visit. Participants discussed the CCWG draft Coordinating Care Plan. Parents liked the idea of having all information in one place and being available to all providers to plan for care. More work needs to be done to get to the planning for care piece.</p>		N/A

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B. Expand MEMSCIS to include care plans, access to care forms & information about coordinating care	<p>The capacity exists within MEMSCIS to add a second page for care plans and information related to coordinating care. Can upload any document, or include a template to build your own.</p> <p>AAP has many excellent resources. Over the past couple of months, we have identified what is lacking: tips for parents, list of things to consider, description of what a care plan is, something that helps move from an EHR or other historical record to a plan with goals, activities and responsible persons.</p> <p>Group took the MEMSCIS Tour.</p>	<p>Explore feasibility of expanding MEMSCIS.</p> <p>Send AAP link to workgroup</p> <p>Check out AAP site to see what forms are available.</p>	<p>Hiner 04/27/10</p> <p>Wedepohl 04/27/10</p> <p>Members 05/05/10</p>
C. Next steps	<p>Samples – would be helpful to have some sample care notebooks of which plans a disorder would typically use.</p> <p>Invite Lee Pyles to participate in next workgroup telemeetings</p> <p><u>Questions include:</u></p> <p>Overview of security features</p> <p>How many care plans can we attach to the site?</p> <p>Can you link up to a medical alert company?</p> <p>Continue to develop resources/tools for our site:</p> <ul style="list-style-type: none"> <li>• Definition of Care Coordination</li> <li>• Tips for parents (i.e., School bus, wheelchair plans, transitioning, write down everything etc.)</li> <li>• Care Plans</li> <li>• Link to AAP site</li> <li>• Sample care notebooks for specific disorders (PKU care notebook, etc. so that it's not so overwhelming for parents when looking at the AAP website.</li> </ul> <p>Piloting: develop a plan to pilot test</p> <p>Dissemination: Will need a dissemination plan. Rebranding of MEMSCI should include care coordination aspect as well as emergency, if possible.</p>	<p>Create a sample care notebook</p> <p>Follow-up with Lee</p> <p>Future agenda</p>	<p>Members</p> <p>Hiner 04/20/10</p> <p>Hiner</p>
Next Meeting	Telemeeting 04/27/10		

Notes by Wedepohl & Hiner