

**Care Coordination Workgroup Regional Meeting Session ~ Notes**  
**Tuesday, December 14, 2010 ~ 3 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> Kathy Wood (IN); Kelly Jackson (KY); Sandy LaPrad, Beth Tarini (MI); Jennifer Arveson (MN) David Hoffman (OH), Sally Hiner, Sarah Wedepohl (Region 4).	
<b>Meeting Goals:</b>	
<ul style="list-style-type: none"> <li>• Integrated Care Plan: Defining what we want to know from the ICP and how we will know it's made a difference. Initiate the piloting of the ICP and tools needed to engage providers and families in the piloting process. Develop a timeline for the pilot.</li> <li>• Guide to Care Notebooks: Reach consensus on sectioning and identify volunteers to draft language for each section. Develop a timeline for completion.</li> </ul>	

<b>Item</b>	<b>Discussion/Notes</b>	<b>Recommendation/Action</b>	<b>Follow up (who/when)</b>
Welcome and Introductions - Wood			
Workgroup Product A – Integrated Care Plan (ICP) - Wood			
Target for Piloting	We are asking each workgroup member to pilot the Integrated Care Plan (ICP) on <a href="http://www.MyEIF.org">www.MyEIF.org</a> . Our goal is for providers to use it with at least two of their families; and family members to pilot it with at least two of their providers. If there is a family or provider that would like to use it in hard copy, that would be fine.	Instructions for piloting the ICP with MYEIF will be distributed.	R4 staff, by early January
Assessing the pilot – what do we want to know from our pilot?	<p>The workgroup discussed how we will know that the ICP will be successful:</p> <ul style="list-style-type: none"> <li>• Providers will realize they are the hub</li> <li>• Providers will acknowledge they are the hub</li> <li>• Providers will communicate with parents that they (providers) are the hub</li> <li>• Have all information available at their finger tips</li> <li>• Better total care of complicated kids</li> <li>• Primary care is not affiliated with the specialist – improved communication between primary care and specialist</li> <li>• Easier way to track and keep stuff together</li> <li>• Greater satisfaction with how information is organized</li> <li>• Greater satisfaction with retrieving relevant, timely information</li> <li>• Time saver</li> <li>• Information is more organized</li> </ul>	Each workgroup member will be asked to pilot the ICP.	Piloting will begin in mid-January
Products to support participation in the pilot	Region 4 is working with the <a href="http://www.MyEIF.org">www.MyEIF.org</a> coordinator to ensure can do self enrollment and to enroll providers who are willing to participate. Instructions for piloting will be available shortly after the first of year. The group decided that it is	Results from ICP pilot will be shared at Regional meeting	Workgroup/ Region 4 by September

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	reasonable to test the ICP and have some results ready for the Region 4 regional meeting scheduled for Sept. If needed, we can pull parents and providers from outside the workgroup to help with the pilot. It was suggested that an example of a completed ICP that people piloting it can look at with a link to contact someone with difficulties would be helpful, even though the site and process seems straightforward.	Include a completed sample ICP for reference and a contact us link	R4 staff/ MyEIF.org staff
Workgroup Product B – Guide To Care Notebooks - Arveson			
<p>Sectioning of the Guide to Care Notebooks</p> <p>Workgroup member assistance and next steps</p>	<p>This document has been divided into sections based on content area. The group agreed that the sectioning made sense. Each workgroup was asked to through the document and add any tips or information that will be useful throughout the Guide. David wrote the introductory letter to the Guide and explained that the idea around providing tips is to provide unwritten rules (things that aren't written anywhere) that you learn from the experience of someone else who has walked in your shoes. These tips are based on your own experience and journey and they are tips that will be helpful to others.</p> <p>The workgroup was asked to look at all the sections and provide tips. If each workgroup member adds tips for each section, they can all be compiled into one document and we can take the next step of writing the Guide.</p> <p>The workgroup was reminded to keep in mind the following information: We are trying to make the bridge from what is in the outline to why. The need is to pinpoint, “We know this is out there but why?” What is important to providers? To families?</p> <p>Sally brought up that there will need to be some decisions made about grouping the conditions, thinking about what would you want to collect regardless of the condition? Then we will look at what is needed for certain disorders as a secondary step. The group decided to focus energy on what is most important first.</p>	Solicit input and advice/tips on each section from workgroup members and thoughts about the placement of the sections/components.	<p>Region 4 will send out the Guide outline and directions to the workgroup by early Jan.</p> <p>Workgroup will complete tips by Jan 19<sup>th</sup></p>
MyEIF.org Meeting Review - Hiner	Sally gave a brief overview of the MyEIF.org branding meeting in Chicago. She will forward the resulting report to the workgroup.	Send out the report to the workgroup	Sally by Jan 1
Next Meeting	Telemeeting 1/25/10		

Notes by Wedepohl & Hiner