



Care coordination Workgroup
Telemeeting Notes -Tuesday, March 25th, 2008 11 am CT/12 pm ET

Participating: Kathy Wood, workgroup co-lead (IN); Jennifer Arveson, workgroup co-lead; Linda Drawhorn, IL; Carolyn Anderson, Kristi Bentler, MN; David Hoffman, OH; Sally Hiner, Coordinator Region 4 Genetics Project.

I. Action Plan update

Next Steps			
Strategy	Action	Who	When
Establish 3 committees of this workgroup to further explore Emergency Plans, Care Coordination component, and Care Plans; and report back to group	Contact wg members not participating in call and recruit to a plan committee	Sally, Sarah	completed
	Draft process template based on meeting discussion	Sally	completed
	Review draft process and provide input	Sarah, Kathy	completed
	Provide final process to committees	Sally	completed
	Schedule and convene committees	Sally, Sarah, Kathy	ongoing
Implement plan review process	Participate in telemeetings and process activities to examine sample plans and provide feedback to CC WG	Committees	March – May
	Identify committee member to report to CCWG on behalf of committee	Committees	ongoing

II. Announcements

- A. Workgroup Co-Lead: Sally announced Jennifer Arveson has agreed to co-lead the workgroup with Kathy Wood.
- B. Foods and Formulas Survey: Sally received a request from Region 3 to have parents/family members in Region 4 assist Region e in developing a foods and formulas survey to collect information from parents/family members about coverage throughout the United States. Sally sent an email invitation to all parents participating in Region 4 and included supporting materials provided by Region 3. She scheduled a telemeeting for Region 3 project coordinators to meet with Region 4 parent/family member representatives following this telemeeting.
- C. Parent/Family Member Meeting late spring: Region 4 is hosting a parent/family member meeting May 19 & 20, 2008 at the Henry Center in East Lansing, Michigan. The meeting will provide an opportunity for

Region 4 staff to obtain reactions and suggestions from parent/family member representatives to maximize their involvement and the unique resources they bring to the regional collaborative. Planning activities also will occur around identifying optimal times, from positive screen to transition, for parents/family members to be provided with information that is disorder specific, about the medical home, and about available resources and supports. Region 4 will pay travel expenses and provide a stipend to offset any costs incurred by the participants. Additional information will be forthcoming via email.

- D. Regional Meeting: The Regional meeting will be held September 15 and 16, also at the Henry Center in East Lansing, MI. Due to budget and space constraints, the number of participants will be limited. A process will be implemented to have state leads identify a cohort to represent their state. Additional information will be forthcoming via email.

- III. Review of Last Meeting: Sally and Kathy gave a brief overview of the February meeting discussion and outcomes. Three subcommittees of this workgroup have been formed to help tackle the three core areas of care plans for care coordination 1) Emergency Plans, 2) Care Coordination (medical) and 3) Care Plans (broader quality of life). Sarah Wedepohl sent out invitations to have workgroup members self-select to a committee. About 8 of the 14 workgroup members are currently participating on subcommittees. Each of the subcommittees held a telemeeting.

IV. Sub-Committee Updates

Sally developed a tool to help guide discussion and provided to the subcommittees.

A. Care Coordination

- a. Progress to date: Subcommittee members reviewed care plans they found. There is quite a bit of variation in what is available. Sally clarified what the charge of this subcommittee was, as the report addressed broader issues than medical care coordination. Committee members agreed the discussion had been much broader than medical care. There is a separate workgroup addressing broader care plan issues.
- b. Need from CC WG: Please forward Sarah sample care plans for the workgroup to review.
- c. CC WG response (Recommendations/Actions: This group discussed the broader care plan issues. Although some overlap is imminent, the CC WG decided to rename this Medical Care Coordination, to help the subcommittee stay focused.

B. Emergency Plan

- a. Progress to date: Most of the emergency care plans identified are disorder specific. Few are electronic.
- b. Need from CC WG: Sample emergency plans, particularly anything else happening in Region 4 states. (Forward to Sarah Wedepohl)

C. Care Plan

- a. Progress to date: There are a great deal of care plans out there. Like Care Coordination, they vary in format and content. The subcommittee used the tool developed by Sally to try to contain their discussion. The committee began to generate a wish list of content items to include.
- b. Need from CC WG: Any samples they would like the subcommittee to look at. (Forward to Sarah Wedepohl).

- V. Next Steps: Sally will follow up with Sarah about getting the subcommittee telemeeting dates and notes out to the group. She also will discuss the need to clarify the focus of each workgroup, and use the tool to guide the discussion with all 3 groups. We need to be careful that we don't reinvent the wheel. Step one of the guide recommends identifying and reviewing what exists. Next full workgroup meeting April 22, 2008. 1/866/489-0573; *4545164*

Notes by Hiner