



Care coordination Workgroup
Telemeeting Agenda

Tuesday, June 24th, 2008 11 am CT/12 pm ET
1/866/489-0573; at the prompt, enter *4545164*

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| I. Welcome & Role Call by State | Jennifer Arveson |
| II. Announcements | |
| A. Family Member/Parent Meeting at Regional Meeting | Sarah |
| B. MEMSCIS and Sickle Cell Meeting in Illinois | Kristi Bentler &
Linda Drawhorn |
| C. Other announcements? | Group |
| III. Sub-Committee Updates | Sarah Wedepohl
& members |
| Care Coordination | |
| Progress to date | |
| Need from CC WG | |
| CC WG reaction/recommendations | |
| Emergency Plan | |
| Progress to date | |
| Need from CC WG | |
| CC WG reaction/recommendations | |
| Care Plan | |
| Progress to date | |
| Need from CC WG | |
| CC WG reaction/recommendations | |
| IV. Next Steps | Jennifer, Kathy,
Sally |



Care coordination Workgroup
Telemeeting Notes
Tuesday, April 22nd, 2008 11 am CT/12 pm ET

Participating: Kathy Wood, co-Lead; Donna Gore Olsen, IN; Jennifer Arveson, co-lead, Kristi Bentler MN; Sally Hiner, Project Coordinator; Sarah Wedepohl, Parent Coordinator.

I. Announcements

- A. Parent/Family Member meeting – scheduled for May 19 and 20. Meeting information has gone out and RSVPs are coming in. Sarah is interviewing parent/family member reps to see how MPHI can support their involvement in the Region 4 genetics collaborative.
- B. Subcommittee meetings schedule:
 - a. Care Plan – Tuesday, April 29 9 am CT/10 am ET
 - b. Emergency Plan – Monday, May 12, 11 am CT/12 pm ET
 - c. Medical Care Coordination - TBD
- C. May CC WG Meeting – Sally will be out of state on May 27. The group agreed to cancel the May workgroup telemeeting, but encourage the workgroups to meet at least two times prior to the June telemeeting.
- D. Other -
 - a. Kathy Wood announced that the Indiana mitochondrial group is examining care coordination. They are interested in the work of this group. Donna provided an example to support the need for transition planning. A young man with a mitochondrial disorder is transitioning to adult services. He is outliving his estimated lifespan, and as planning did not occur, the family has found themselves reacting to issues as they arise.

II. Sub-Committee Updates

A) Care Plan – Jennifer Arveson reporting:

- 1) Progress to date: the subcommittee is working on a list of education issues that parents could use as a checklist of things to think about. Sally and Sarah are developing an assessment tool to be used to review and assess existing care plans. This is based on issues and concerns raised in discussions of the subcommittee. The subcommittee will test and finalize the tool. A list of issues and assumptions also is being compiled to help track the broad array of potential issues.
- 2) Need from CC WG: A list of identified care plans will be developed and workgroup members will be asked to review and assess specific plans off the list using the final assessment tool. This will result in a summary of what already exists.

B) Care Coordination – Donna Gore Olsen reporting

- 1) Progress to date: this subcommittee has been struggling to define its niche; where they fit given that we have a group addressing larger issues. During the first telemeeting in March, they took a much broader perspective and discovered that the care plan group was charged with the broader perspective. Sally tried to refocus the group on medical care coordination – coordination between the medical/health care providers involved with the child. There was quite a bit of discussion about the impact of medical care coordination, treatment and intervention on other facets of life – medical care can and

often does have an impact on other aspects of a person's day-to-day existence (e.g. school, employability, etc.).

2) Need from CC WG: Nothing at this time.

3) CC WG reaction/recommendations: Kathy Wood reiterated that this is a very important issue to tackle in care coordination. Although there is understanding of the importance of coordinating care, no one seems to be addressing it in a proactive, systematic way. Sally asked if there are multi-disciplinary teams, such as exist for CAH patients, the other IBEM patients. No one reported awareness of any. Things to think about including: who is the "go to" person for what situation? This is generally not clear to parents. The health care providers typically involved with IBEM are dietician, nurse, primary care physician, metabolic specialist, sometimes neuro- psych, pharmacist. Donna noted that the Cerebral Palsy clinic has a comprehensive approach to medical care coordination.

C) Emergency Plan – Kathy Wood reporting

1) Progress to date: Subcommittee is examining existing emergency plans. All subcommittee members are doing the MEMSCIS tour, using the guide Sally provided to subcommittees for things to think about. Next meeting will be a discussion of tour experiences. Goal is to formulate recommendations to bring back to workgroup. Subcommittee also is considering developing recommendations to improve and enhance care coordination in emergency medical situations e.g how do parents prepare to go to the hospital, what they should bring (i.e. special foods/formulas/medications that are typically not readily available in a hospital pharmacy)? Lots of information has been suggested that would facilitate the emergency visit *process* in addition to the information necessary to medically treat in an emergency.

2) Need from CC WG: will likely be asking WG members to tour MEMSCIS and react to subcommittee recommendations.

Other: Sally reported that she worked with Sarah to develop a survey of Region 4 State Leads to gather information about what already is being used or developed in the region. Responses are slowly coming back to Sarah. Sarah will compile and develop a summary of the survey results. Also, Sarah co-facilitates the Medical Home Workgroup. Occasionally, some of their discussion overlaps with the care coordination focus. Sarah has been passing on resources provided by MH WG participants to the relevant CC WG subcommittee.

III. Active participation: Only about 50% of the work group members are participating in subcommittees. Some CC WG members have never participated at all. Kathy Wood volunteered to follow-up with inactive or "less active" members to spark some interest and see if there are issues we can address to increase individual member participation. Sally will provide the co-leads with member attendance and contact information. Donna knows a parent/family member representative she would like to recruit to the workgroup. Donna will work with Bob Bowman on recruitment.

Notes by Hiner