



Care coordination Workgroup

Telemeeting Agenda

Tuesday, March 25th, 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, Project Team | Kathy Wood |
| II. Announcements | Sally, Sarah,
Group |
| A. Workgroup Co-Lead | |
| B. Foods and Formulas Survey | |
| C. Family Member/Parent Meeting late spring | |
| D. Other? | |
| III. Review of Last Meeting | Kathy Wood |
| IV. Sub-Committee Updates | Sarah Wedepohl
& members |
| Care Coordination | |
| Progress to date | |
| Need from CC WG | |
| Emergency Plan | |
| Progress to date | |
| Need from CC WG | |
| Care Plan | |
| Progress to date | |
| Need from CC WG | |
| V. Comment – Reactions to the process/activities? | Jennifer Arveson |
| VI. Next Steps | Jennifer & Kathy |



Care coordination Workgroup
Telemeeting Notes -Tuesday, February 26th 2008 11 am CT/12 pm ET

Participating: Kathy Wood, workgroup lead (IN); Linda Drawhorn, IL; Kelly Jackson, KY; Jennifer Arveson, MN; David Hoffman, OH; Alex Meyer, WI. Sally Hiner, Coordinator Region 4 Genetics Project; Sarah Wedepohl, Parent Coordinator.

Promote the use of care plans specific to children with heritable disorders

Discussion: care plan issues include

- What would be included (components)
- Who audience is
- Who is main person(s) responsible for
 - ensuring information is included
 - updating information
 - determining access
- Need to get input from audiences/users
 - is the information identified the right information to include
 - How should it be presented

Obj a) Define Types of Care plans b) define audiences for each type of plan c) identify components for each type of plan

Obj a) Discussion: Identified two types of plans:

- Emergency Plan
 - information necessary in a medical emergency
 - fast access to facts for
 - emergency room staff
 - family members
 - specialist
 - must be quick, easy, efficient – limit to 1-2 pages
 - goal is to provide necessary info for efficient access in a medical/health emergency
- Care Plan
 - overall community and service integration to improve outcomes for children with heritable disorders and their families.
 - *Care Coordination* is a component of care plan

Obj b) Discussion

- Care Plan - Audiences for the information vary by component.
- Some information families may not want to make available to all audiences – families should be able to retain control over who has access

- to what information
- Care coordination - several medical specialists involved, pulmonary, genetic, family care, pharmacy; care coordination and care plan – one overall care plan, care coordination section for coordinating medical service providers
- Obj c) Discussion
- Care Coordination refers to information necessary to treat medically,
 - Chuck Onufer’s care book on AAP website is good start for Care Plan. Good options. Tempting to continue to add components. Suddenly you have 35 pages of information.

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	3/06/08
	Disseminate list of committee members and contact info	Sally	3/07/08
	Draft process template based on meeting discussion	Sally	3/04/08
	Review draft process and provide input	Sarah, Kathy	3/06/08
	Provide final process to committees	Sally	3/07/08
	Schedule and convene committees	Sally, Sarah, Kathy	3/09/08-3/24/08
Implement plan review process	Participate in telemeetings and process activities to examine sample plans and provide feedback to CC WG	Committees	3/09-3/24/08
	Identify committee member to report to CCWG on behalf of committee	Committees	3/25/08

Committees:

Emergency Care Plans - Kelly Jackson, Kathy Wood

Care Coordination - (coordination of medical services) Linda Drawhorn, Alex Meyer

Care Plan – (day-to-day important things to know) David Hoffman; Jennifer Arveson

Things to consider in review process:

- a) What exists? See what we can adapt or recommend – no need to reinvent the wheel
- b) Can we expand the internet based MEMSCIS to allow information to be available electronically?
- c) Who doesn’t need to see the info? How can parents decide what they do and don’t want audiences to see?
- d) How information is presented is important
- e) Audience/stakeholder input
 - a. What kind of input is needed?
 - b. How do we get it? (e.g. survey, phone interview, focus group, etc)
- f) How information is presented is important

Notes by Hiner