



Medical Home Workgroup
Telemeeting Notes
Wednesday, January 21st, 2009

In attendance:

Bob Cook (IL), Jane Turner (MI), Kathy Sanabria (IL), Sharon Fleischfresser (WI), Eden Schafer (WI), Sondra Gilbert (KY), James Bryant (OH), Sarah Wedepohl (MPHI), Jodi Griffin (MPHI)

THE GUIDE

Jodi Griffin from MPHI has been editing the guide and had some questions/need for clarification for the following components:

OUTLINE

- Moved all resources to the "resources section" in back of the guide
- Items with an asterisk need to be developed further or need more information (ie., Is Able Play in a good spot here?)
- Moving the sections about Genetics to the front to better identify that this guide is for this audience. Group suggested making a note that the guide is applicable to all kids with special needs but that it's specifically for children with genetic disorders
- Inserting Care Coordination plans and other tools in section VIII d.
- Need to consider other pieces such as Emergency Preparedness – Group thought that a separate section would be good for this but also can cross reference with Care Coordination section to include Emergency Care Plans.
- Been working on making the sections of the guide more interactive

RESOURCES

- For the state-specific resources, we asked one or two people from each state who were on the call to look at their state's resource pages and update those items in purple. Those items either need contact information and/or a short description about the organization. James said that he would work on the state resources for Ohio, Sharon and Eden will work on the resources for WI, Sondra for KY, Bob and Kathy for IL and Jane for MI. Jodi and Sarah will be asking those from MN and IN who were not on the call to look at their resources
- Jodi also asked everyone to look at the National Resources and make sure that nothing is missing or needs to be changed.
- We are also in need of someone to look at the Condition Specific Resources to compare them with the Region 4 website's and add any that are missing. Please contact Sarah if you are able to help with this

DEADLINE FOR ALL CHANGES/ADDITIONS ABOVE IS WEDNESDAY, JANUARY 28TH

PARENT TO PARENT TIPS

- We are collecting quotes from parents to include throughout the guide as "Parent to Parent Tips". We are looking for any tips that parents have about any topics included in the guide. An email request will be going out to all the parents in the collaborative.

GLOSSARY

- In order to make the glossary section inclusive, please forward any items/words that need defined to Jodi by January 28th.

UPDATE ON MARKETING/ROLLING IT OUT

MPHI talked with a marketing professional who works with ACMG and is excited to work with us on the marketing of our guide. She is writing up a marketing plan and we will be talking with her sometime in the next few months about how to get the guide out to as many people as possible with the money we have allotted. The Region 4 Genetics Collaborative Advisory Board will be meeting on Feb. 23rd and will be asked to approve the Medical Home Guide.

NEXT MEETING

Our next meeting was scheduled for Friday, February 13th but both of our co-leads have a conflict with this date due to a Medical Home meeting in Michigan. We are going to set the new date of Wednesday, Feb 11th instead. The group discussed alternating the second Friday of the month with the second Wednesday of the month so everyone has a chance to attend.

The next meeting dates are:

Wednesday, February 11th 11-12:30 CENTRAL, 12-1:30 EASTERN

Friday, March 13th 11-12:30 CENTRAL, 12-1:30 EASTERN

Wednesday, April 8th 11-12:30 CENTRAL, 12-1:30 EASTERN

Notes by Wedepohl