

Medical Home Workgroup Meeting Notes 10-10-08

Attendees: Nancy Deising, Jana Stringfellow-Estell, Bob Cook, Eden Schafer, Barb Dalbec, Renee Temme, Angela Bailey, Sarah Wedepohl

Updates:

- Nancy is still working on the MH Guide draft. It needs to be in a format to use it (web-based, etc) which MPHI will help with.
- Sarah talked about the upcoming HRSA visit to MPHI and the importance of the guide as we move forward—it is a priority for Region 4 to get the guide distributed.

Brainstorming to Get the Guide Distributed:

We discussed the following topics:

- How do we distribute the guide?
- Who does it go to?
- What format should it be in?

FORMAT

Should the guide be print copy or web-based? Web-based is good, but not every family has access to the web.

It would be helpful to have a flyer or card available that has the link to the guide (marketing)

Good to look into print costs - MPHI could print copies for all states - define how many and they could copy as needed

WHO DOES THE GUIDE GO TO?

- Specialty Clinics
- Newborn Screening Programs
- Genomics?
- Send it out when they have a confirmed diagnosed with one of the conditions - all families get a mailing with it
- The guide can go out to each location on Region 4 website - (workgroup members from each state will look at the map and make sure that they are all updated)
- The guide can be announced when it is ready that this is available for families - including notifying families where to get it
- NICU - Have a hard copy so families can see it and know where the link is
- Can add this to the AAP care plan - link to the AAP on web- one version in word and one version in PDF. This would be a point of access for a pediatrician and parents and anyone working with pediatricians
- Forms and checklists can be in both pdf and word

WHEN?

- Some would want the information as soon as they receive the diagnosis
- Some would want to know that that is available and where they can get it - (one participant said, "If I receive too much information it would overwhelm me at times")

DETAILS...

- Some providers have developed a care coordination system/plan but this is specific to heritable conditions - we are not duplicating but make it useful
- How often will this be updated - how will it be updated?
 - Regional resource pages can have a contact person for each state (this is the advantage for being on the web so we can continually update)
 - Make changes to a test site then post them quarterly get reactivated - link right to it
 - Add date to materials that they were updated so we know when last updated
- Evaluation is important - one for organization that hands it out and then family perspective - asking if they are you using it
- Include some spot for people to give feedback
- Money will be a factor