

MEETING NOTES

Region 4 Genetics Collaborative Transition Workgroup

May 10, 2010

Meeting documents – Meeting Agenda, Transition Materials and Initiatives, Meeting Notes 4-16-10

Attendees: Kathy Bachmann (OH), David Entwistle (OH), Jennifer Warfel (OH), Holly Elliot (IN), Claudia Nash (IL), Parag Shah (IL), Sondra Gilbert (KY), Anne Weaver (KY), Bth Carne (MI), Ceci Shapland (MN), Frank Lerman (MN), Michelle Kempf-Weibel (WI), Kara Van Vooren (WI), Abby Shannon (Region 4), Sarah Wedepohl (Region 4)

Overview of the National Transition Workgroup Meeting (Sarah)

Sarah gave an overview of the national transition workgroup March call. Each region reported on their efforts around transition. Heartland region is in the brainstorming phase about what area of transition to focus their efforts on. Region 3 talked about Florida Health and Transition Services www.floridahats.org and Jacksonville Health and Transition Clinics (JAX HATS www.jaxhats.ufl.edu). Region 2 is starting a primary care transition clinic for young adults with disabilities that will be staffed by a part-time social worker and physician. Region 1 is coordinating transition and medical home workgroups with University of Massachusetts and Children's Hospital of Boston including a transition tool currently being used in a pilot project called the Personal Health Transition Plan Project.

Overview of Healthy Ready to Work Presentation (Ceci)

Ceci gave an overview of the recent presentation "Celebrating the HRTW National Resource Center: Findings, Recommendations and Thanks!" conducted on April 21st. All the information from the call and resources are on www.hrtw.org. The call included an overview of the last 4 years to show the progress of the resource center and how the concepts of transition and issues surrounding transition have grown. She also mentioned that Title IV programs are an organization that promotes transition and the progress they have made is great overall. She recommended that our group focus on youth as leaders including bringing youth to our committee and work with youth on how we want to promote our message when we work with other organizations.

Review of the Transition Workgroup Meeting at the Regional Meeting (Abby)

- Started the meeting by reviewing the work plan then looked at a PowerPoint transition of a model of transition across the lifespan that was created by David, discussed it and tried to find out what might be missing. Then they looked at a tool to rate materials on quality, content and other areas. Group made changes and Abby made changes and ran copies. The workgroup then got in to groups of two and each group had a stack of materials to go through and rate using the rating tool. Abby has all the tools and resources--close to half of the resources have been eliminated based on ratings. **Abby will be compiling the results after this call and discussion about content area and target audience.**
- A few resources floated to the top including Healthy Ready to Work, John Rice's work in Florida, and Wisconsin Children's.
- Kathy recommended using the term "young adults" instead of "youth" based on her past experience.

Next Steps Discussion (David)

- Goal of the discussion was to figure out where to throw our energy at this point. Have already decided to focus on the issues family face during transition, including parents, children, adolescents and young adults. It is a developmental process that will unfold across time and differently for people with different conditions. We will need to have some very general information but also let people seek out more specific information as needed.
- First thing to decide is where we want to start. Sondra suggested adolescence as a good starting point, others agreed. Ceci suggested that we send the message that the process needs to start earlier.
- At the regional meeting we talked about an end product being a website where we can link to different resources. Kara mentioned that transition in general all have some things in common so we could build on that and consider what is the same throughout all of them and then have target areas for the specialty times. Anne mentioned that if the target age were 14, information listed would naturally go backward and forward on the age range. Something that focuses on commonalities about transition in general, then break it into specific, predictable kinds of transition across the lifespan.

- Kathy talked about the need for money for updating a website if that is the route we take. If HRTW could give us a corner, that would be helpful. Ceci talked about whoever gets funded, it would be helpful to talk with them and pose the question of linking together and sharing resources. For now, look into a page on Region 4 website.
- Identify specific things to look for resources for, what types of issues do we want to target if we are looking at the issues with young adults transitioning?
 1. Health coverage (insurance) – HRTW has been putting out the message that age of eligibility has changed in many states, see their website for more info. Also, adult disabled dependent clause info as well on HRTW website. Holly mentioned that through her clinic she recommends some families who might qualify for adult dependent clause. Sondra mentioned not everyone is well informed right now since things are state by state and can be complicated. David mentioned how difficult it will be to keep track of such a fluid issue and one that is so state specific. Instead of specific information, might need some more general information about how you go about looking into these issues. Ceci suggested “questions to ask” section with some resources. Sondra mentioned that AARP’s monthly magazine has a wonderful section on the health care reform updates.
 2. Moving your medical home – In Ohio, Kathy mentioned it’s complex and some young adults put together a mix of care. How do you navigate care? Ceci mentioned that some people may not transfer but that doesn’t mean that a transition doesn’t take place – it takes skill building and learning about being the best consumer possible. Kathy said we work with AAP but don’t approach family practice doctors about the issues of people with complex needs. HRTW feels that family practice doctors accept the process, they don’t see it as such an issue as internal medicine doctor might.
 - **Abby will look back to see what she can pull from the materials that relate to the above two issues. If anyone has resources please send them to Abby.**
 3. Treatment adherence, Disorder Education, Educational/Vocational Decisions – Very important, looks at the youth and what they need to know and the expectations. Then how to apply that information to all aspects of their life. Kathy mentioned how often young adults depend on their parents. David mentioned also parents needing to let go and the support they need.
 4. Achieving self-support – SSI, waiver, etc.
 5. Disclosing about Condition - David talked about research study he is doing and a topic coming up is how do I tell others about my genetic condition? Partners, employers, etc.
 6. Recreation – what do they like to do with their free time and are there barriers for them?
 7. Guardianship Issues
 8. Life-skills – Young adults tend to score lower in this area. Wide variety of abilities, which makes the process more difficult.
 - **Sarah will send these notes out, please look at this list and add anything missing and prioritize them. Also, send along any materials or resources that you might have related to these issues.**
 - David brought up the need to get input from young adults as well. Sarah suggested bringing young adults on the calls over the summer when it is a more convenient time for them to participate. If any of the group member’s children or if you know of any young adults who would like to participate let us know. Facebook was brought up but it’s not a possibility now with IRB rules, etc at MPH. Sarah suggested a call just with a couple of group members and a group of young adults and have a specific agenda. Give an incentive to the young adults for their time. This could happen over the summer. Kara said that someone at her work who is a partner on transition is putting together a team of adolescents and she might have some people we could tap into. **Please forward any names of young adults who might be interested in participating in a discussion to Sarah. We are looking at recruiting young adults who are going through or have already gone through the process. Kara suggested one group with 14-17 and another with older young adults so the younger group doesn’t feel intimidated.**

Reimbursement (Sarah)

- **Any parents or family members who submit for reimbursement need to submit any outstanding reimbursement requests by the end of this month in order to get paid (since the closing of our year is May 31). If you have any questions please contact Sarah.**
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Next Steps:

- Please see the above items that are in bold for next steps.

Notes by Sarah Wedepohl