

MEETING NOTES

Region 4 Genetics Collaborative Transition Workgroup

March 15, 2010

11am Central, 12pm Eastern

Meeting documents – Meeting Agenda, Transition Workgroup Workplan 2010, Transition Document Index, Transition Workgroup Members Roster

Attendees: Kathy Bachmann (OH), Beth Carne (MI), Holly Elliot (IN), David Entwistle (OH), Sondra Gilbert (KY), Claudia Nash (IL), Ceci Shapland (MN), Kara Van Vooren (WI), Anne Weaver (KY), Abby Shannon (Region 4), Sarah Wedepohl (Region 4)

Overview of the Region 4 Genetics Collaborative (Sarah Wedepohl)

- Sarah gave a background about the collaborative and Region 4. She directed everyone to the website where Region 4 participated in a webinar through Genetic Alliance's "Meet you Neighbors" series. The link to the webinar is <http://resourcerepository.org/av/cmVnaW9uNGdlbmV0aWNzY29sbGFib3JhdGl2ZQ==/>

Roll Call/Introductions (Sarah Wedepohl)

Workgroup members introduced themselves and talked about their background and experiences.

Review of Workgroup Charge and Year One Plan (Abby Shannon)

- Abby provided an overview of the Transition Workgroup's Workplan, including the process of how the workplan was developed (through our logic model) and the goal of the group. She directed the group to our website for more information about the She emphasized that our focus is on "transitioning medical services" over other areas of transition. For more information about the she directed the workgroup to our website (link http://www.region4genetics.org/region4/region4_five_year_plan.aspx) for more information about the grant.

Workgroup Roles (David Entwistle, Abby Shannon, Sarah Wedepohl)

- David spoke about his role as co-lead and Sarah talked about the workgroup structure that has worked well in the past. Parents, professionals and/or consumers are represented from each state and we have two co-leads who have a strong lead role in the group and often the "spokespersons" for the group. Abby and Sarah are the co-facilitators who help the group organize thoughts, information and make sure the group stays on task to meet the original goals.
- Abby described the role of workgroup members who will share information that is unique to their states, help the region make informed decisions, provide feedback about materials and processes, bring a unique voice to the group and participate in tasks in between workgroup meetings to make our time more productive.
- Sarah also described how we support and involve parents through the collaborative.

Meetings (Sarah Wedepohl)

- Sarah described the workgroup process of meeting monthly via conference call at a regular date and time. Since we wanted to fit in the first two meetings prior to the regional meeting, we will not start a regular meeting date/time until after the meeting. Sarah will use the survey information about workgroup member's availability to find a date acceptable to the most people.
- The National Transition Workgroup was discussed—there are representatives on that workgroup from all regions in the collaborative including two parents form our workgroup and Sarah, and meets monthly by conference call. We will be providing regular updates to this workgroup on national activities so we do not duplicate efforts and can gain information nationally.

ACTION NEEDED: We will determine a regular date and time for our monthly meetings during the next meeting.

Conference Call Protocol (Sarah Wedepohl)

- Sarah described the important considerations for successful phone calls. Please identify yourself before making a comment so everyone knows who is speaking. This will become less important as time goes on.
- Background noises can be amplified on a call especially if you are on a speakerphone it can make it hard to hear. It is helpful to use the mute feature when you aren't speaking.
- Please be aware that if you put our call on hold we will hear any recorded messages or music that your phone automatically uses.
- We were asked if our conference call line has a mute code and we will find this out and let the group know.

ACTION NEEDED: We will find out if the conference call line has a mute code and let the group know at the beginning of our next meeting.

State Transition Activities (David Entwistle)

- David suggested that we gather information from other regions about what each region is doing on transition.
- Abby talked about the importance of gathering information from each state including what models, plans or processes have been successful in your state. We are emphasizing successful so we can focus on what is working.
- Each state reported any transition activities that might be important for us to share on our resources we are gathering:
 - Illinois – Claudia Nash deferred to Dr. Shah and Bob Cook, who she will follow-up with for information before our next call.
 - Michigan – Beth Carne offered to research Michigan's transition activities through her contacts at the metabolic clinic at Children's Hospital of MI and report her findings at our next call.
 - Indiana – Holly Elliot talked about CYACC, the transition clinic where she works. She discussed a research study they are doing about navigating resources for families and a youth subcommittee (which she chairs) which studies and addresses barriers that youth with special health care needs come across during transition.
 - Kentucky – Sondra Gilbert talked about "One Stop" a collaborative internet-based service for families on transition, Kentucky Early Childhood Transition Project and SIGNAL (KY transition project for transitioning into adulthood. Sondra sits on all of those transition teams. Also focuses on transition issues in education. Anne Weaver volunteered to write out what worked and didn't work in her child's transition process.
 - Minnesota – Ceci Shapland talked about a program at Gillette Children's Hospital that is a lifetime clinic so young people start in mid-teens and continue through adulthood. They have specialists available and take a more holistic approach. This was important when looking at aging issues that come up. Also worked on medical home collaborative that did a lot of work around transition. The primary care clinics that were involved with that are incorporating transition in their MH practices. Ceci volunteered to find out what else is going on at the Universities in MN. She will also send us the link for the Gillette program.
 - Wisconsin – Kara Van Vooren described a booklet that is called "The Transition Health Care Checklist: Preparing for Life as an Adult". It also is available as a pocket guide to carry to appointments. Also mentioned WI's Parent Information Center that is working on putting health care into transition processes. Also the WI Statewide Transition Initiative, a group of statewide stakeholders with meetings and annual meetings, and HRTW initiatives. Transition Access Councils are also throughout the state to help support healthcare and other issues.
 - Kathy Bachmann has a website for John Rice's resources from Florida, including a "what to do when you are 18 brochure".
 - David pointed out that transition is going to look different for different disorders. He suggested that we look at some of the condition-specific models that are out there. Abby stated we would organize the materials in a way that reflects the different disorder-specific information. Holly spoke about the issues with insurance and how in Indiana some conditions are covered through state sponsored

health insurance past childhood while others are not. Kathy Bachmann discussed how different transition issues will depend on locality (places/cities with lots of specialty resources vs. not).

- Ceci Shapland discussed the importance of starting transition early. She suggested this as a strong message for the workgroup. Abby discussed the roles each player has in the transition process and how we can organize our thoughts as we move forward and who plays a role in transitions (parent, pediatrician, young adult/child, and adult provider). Anne mentioned that daycare age and ages 14-21 seems to have the greatest challenges.
- Sarah discussed Region 4's state stakeholder meetings and the discussions we had with families in each state on family functioning. The subject of transition came up a lot during those discussions and it might be helpful to look through that information to see if there is anything that would be worthwhile for this group.
- David talked about the pluses and minuses of adults staying at children's hospitals since there are aging issues to consider. The idea of "best practices" should be considered including what, in general, should we be looking at for both medical and social transitions issues as they move toward adulthood?

ACTION NEEDED: See above bullets for tasks. Even if you are not listed above, please look for resources in your state or nationally that you are aware of, especially those that are successful! Please send all links to Sarah by March 24th so we can keep updating our current list.

Next Steps:

- Please see the above "Action Needed" items for next steps and send all links to Sarah by March 24th!
- Our next telemeeting is on Monday, April 5th 11-12:30 central, 12-1:30 eastern. After that time we will be scheduling our calls for a regular day and time every month—we will discuss this on April 5th.
- The Regional Meeting is on April 14-16th with a parent leadership training for parents on April 13-14th. Our workgroup will be meeting during that time.

Notes by Sarah Wedepohl