

Transition Workgroup Meeting ~ Notes
Monday, December 13, 2010 ~ 11 am CT, 12 pm ET

Co-Leads: Kathy Bachmann, David Entwistle	Facilitators: Cynthia Cameron, Abby Shannon and Sarah Wedepohl, Region 4 Genetics Collaborative
Participating: Kathy Bachmann (OH), David Entwistle (OH), Sondra Gilbert (KY), Lauren Leviton (IL), Frank Lerman (MN), Cynthia Cameron (Region 4), Abby Shannon (Region 4), Sarah Wedepohl (Region 4)	
Meeting Goal: To define the outcomes/goals we plan to achieve when conducting interviews with young adults.	

Item	Discussion/Notes	Recommendation/ Action	Follow up (who/when)
I. Welcome, Introductions			
A. Roll Call			
II. Workgroup Update			
Recap of Where We Are and Where We Are Going	<p>Kathy provided a quick review of where we have gone as a workgroup:</p> <ul style="list-style-type: none"> • We first gathered and reviewed materials on transition and rated their quality. • We learned that there are a lot of good materials and we wanted to make sure that we tried to fill a gap rather than duplicate what has already been done. • We narrowed down our focus to the social-emotional aspects of transition and developed a logic model for the workgroup around what we have learned about parents, young adults and the social-emotional aspects of transition. • We spoke with John Rice from Florida who gave us information about what has been done in the past on the social-emotional aspects of transition. • In the last few calls we have talked about gathering input from teenagers/young adults to help inform our final product (both the content and the format). We are also keeping in mind that it is important to get feedback from families whose children are not able to take charge of their own transition but rely more on their parents for assistance. • Today we will be discussing our outcomes for the project and work on the content of the questions we are interested in asking youth. 		
III. Discussion of Transition Workgroup Outcomes			
	<p>Cynthia Cameron, Region 4 Director spoke with the group about outcome-based planning and facilitated a discussion to define our workgroup's outcomes.</p> <p>She explained that all of the workgroups work toward a product or tool based on things that improve services. They share these products and tools nationally using the strong connections we have with other regions nationally. She posed the question to the workgroup: "What do you want to change for young adults going through transition?"</p> <p>The workgroup brought up the following potential changes in response:</p> <ul style="list-style-type: none"> • Improve adherence • Increase independence by increasing their knowledge base and ways to describe their condition to others (peers, PCP) • Improve experiences while going through normal developmental processes with their condition (dating, friendship, reproductive issues) • More positive health outcomes 		

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	<p>She reminded the group to keep in mind two populations of young adults--those who can be independent during transition and beyond and others who will always need to depend on their parent(s). The workgroup does not have the resources to address both of these populations at once so the group decided to first address adolescents who can become independent.</p> <p>The workgroup discussed age ranges for talking with young adults. We will be gathering information from young adults who are slightly older so they can give us feedback based on their own experiences (as they look back on their middle school and early high school years their experiences should also help gain insight about a younger age group as well).</p> <p>Region 4 will develop a visual model based improving health outcomes. In response to Cindy's question about what influences health outcomes, the group brainstormed the following:</p> <ul style="list-style-type: none"> • Building/having support systems • Information about how to talk with your adult provider • Self-efficacy (the positive parts of self) • Building a perception of your own future/life-course (this perception is sometimes influenced by perceiving others around you as "better" or "worse-off") • Being able to have goals (that might be different for different people) • Insurance coverage, what you are eligible for once you transition • Dealing with parents, parental expectation, and parental control • Managing chronic pain and its influence on depression • Relationships with peers <p>The above are all related to three themes:</p> <ol style="list-style-type: none"> 1. Topics related to medical care and resources around medical care 2. Support systems (parents and peers) 3. Topics that are inherent in the individual <p>Improving health outcomes runs throughout the 3 themes.</p> <p>The workplan will change a bit based on today's discussion of outcomes. Once the model is developed the group will revisit the workplan.</p>	<p>Develop a model based on the outcomes that the workgroup defined today.</p> <p>Get feedback from young adults about topics and outcomes</p>	<p>Abby will send to workgroup</p> <p>Region 4 staff will email Kathy a list for her next meeting</p>
IV. Adjourn			