

2010 Regional Face to Face Transition Group Meeting 4.20.10

Participants: Beth Carne (MI), Holly Elliott (IN), David Entwistle (OH-Co-chair), Sondra Gilbert (KY), Frank Lerman (MN), Mary Jo Paladino (IN), Ceci Shapland (MN), Anne Weaver (KY), Eden Shafer (WI), and Alisha Keehn (NCC, ACMG)

Meeting summary:

- Transition across the Lifespan was discussed. Model was modified based on discussion.
 - Transportation
 - IEP/School Transition
 - Palliative care
 - Each transition involves a process of grief – for the individual and for the family
- The group finalized the rating tool based on past discussion.
- Copies were made of the final rating tool.
- The group worked in groups of two. Each group had a stack of materials. One group was assigned to websites.

The criteria that were added to the rating tool are below:

Youth Involvement	Were youth involved in developing or reviewing?
Parent/family Involvement	Were parents/families involved in developing or reviewing?
Target Audience	Does it target non-physician audience?
General Guidelines	Is the content applicable to many conditions?
Condition Specific	Is the material condition specific?
Medical Culture	Does it address the culture differences between pediatrics and adult medical providers?
Start Early	Does it emphasize the importance of early transition planning?
Independence	Does it provide information or tools to increase independence?
Insurance Issues	Does it address issues around changes in insurance?
Education/Career	Does it address education and/or career issues?

Discussion Issues:

- Target families vs. medical world
 - The group is better suited to target families and we will put any materials directed at this community aside.

- We will focus on families as our target
- Importance of starting very early (prior to age 14)- Kentucky begins at age 2
- How do we handle specific conditions and transition?
- How do we address normal adolescent behavior? Adherence to health regimen
- Transition Website – technology is the wave of the future
- Should be useful and accessible
- Need somewhere to go to access all the tools I need
- What do we call this population – one focus group didn't like being called “youth” Individual?
- What is in health reform for youth? Look at family voices.
- Do we need a general statement ?
 - Guiding principles
 - Philosophy
- Need to make sure that our website (if that's what we are doing) comes up in the first few listed when someone begins searching for transition materials– how do we do this?
- Some website favorites:
 - John Reiss – FL
 - Wisconsin Children's
 - Medical Home Portal

Would it be helpful to organize reviews into a table that looks something like this?

Title	Target Group	Type of Resource	Focus	Comments