

**Clinical Services Work Group
Teleconference Meeting
December 14, 2007**

Members Present: Brad Schaefer (NE), Merlin Butler (MO), Donna Nale (MO), Dana Orten (NE), Fred Schafer (OK), Melissa Craft (OK)

Regional Coordinating Center Team (ex officio): Kyna Byerly

Agenda Item	Discussion	Recommendation/Action
<p>Utah MedHome Portal Collaboration</p>	<p>http://medhomeportal.org/ Sections written for Prader Willi (PWS) diagnosis module to be sent to Utah; they will review and edit, and send back to us for approval. They will post final versions to their web site, and create cross links with us. Reviewed instructions for authors, and “Issues” list as pertains to PWS. Work group members to write sections under “Related Problems and Issues”, using primarily Prader Willi Syndrome Management 3rd Edition book. Merlin has written initial Brief Description and Prevalence, and will write Genetics and Growth issues sections. Utah also has some modules already in draft form, such as Fragile X. Brad Schaefer volunteered to review it. Having Utah write an initial draft for us to review, edit, add to and complete was discussed.</p>	<p>Regional coordinating center to finalize work scope, contract. Members to be contacted by email to sign up for sections to write. Brad to review Fragile X draft module. Kyna to coordinate communications.</p>
<p>Transition</p>	<p>Guidance probably out soon and response due possibly by Jan 10. NE federally funded (Dept. Educ.) transition project reviewed by Brad. Four components: 1) Transition clinic for Children with Special Health Care Needs (CSHCN). Serves all CSHCN via telehealth network; transitioning to clinical service w/Title V waiver funding. 2) Physician education/training: produced a resource note book to be used as a tool in transition; converted to DVD. ~25% of the info is NE-modified to provide links to regional or state specific info.3) Integrate transition education into medical curriculum 4) Monthly topic specific educational series, presented through statewide telehealth network, and available digitally. Many components could be shared with other states/agencies.</p>	<p>Regional Coordinating Center to contact members via email for input and assistance with response to guidance, specifically on developing a plan for addressing transition for children with heritable disorders. Update: non-competitive renewal due Feb. 4</p>

	<p>Kyna has begun identifying transition projects through Title V or Maternal Child Health or other entities in each state. Kansas has a project through their CF clinics, and a posted and brochure for clinics. Mary Bechtold w/CSHCN is KS contact.</p> <p>Tentative plan for next year to provide info from NE project and assist other states in developing similar services/programs for medical transition:</p> <ol style="list-style-type: none"> 1. Identify partners 2. Offer technical assistance for assessment, planning and resources 3. Consumer evaluation of appropriate components of NE project 4. Disseminate appropriate NE components to the region via identified partners, Heartland web site. 	<p>Members: respond via email to group with input on possible transition plan for next fiscal year</p>
<p>Next Meeting:</p>	<p>2nd Friday of the month</p>	<p>Friday, January 11, 2008, 8:30 am</p>