

Clinical Services Work Group

June 13, 2008

Teleconference

Toll Free Dial In Number: (877)807-5706 PARTICIPANT CODE: 667793

Agenda

1. Welcome and Attendance
2. Regional Coordinating Center Update
 - a. Grant award: Transition (See below addendum)
 - b. Annual meeting
3. Clinical Genetics Services Listings
 - a. Status on updates from states
 - b. Heartland Website Database: how to categorize for searches: see info below
4. Telemedicine Resource Manual Project Update (Schaefer, Nale, Butler)
 - a. Sections: red needs to be written
 1. Introduction
 2. Policies and procedures
 3. Sources of funding
 4. Information for patients
 5. Information for providers
 6. Billing
 7. The role of the telemedicine coordinator (knowledge and job responsibilities)
 8. Other personnel needs
 9. Equipment
 10. References
5. Update on PWS Module/Just in Time Education Project
6. New Business
7. Next Meeting: **July 11, 2008 8:30 am**

Transition from Narrative of grant renewal

Build linkage to resources for transitioning individuals from pediatric to adult healthcare
A stated goal within *Healthy People 2010* plan is for all young people with special health care needs to receive the services required to successfully transition into all aspects of adult life: healthcare, work, and independent living (2). Within the Heartland, we have identified two model programs; one at University of Nebraska Health Sciences Center and the other at the Sickle Cell Treatment Center at University of Oklahoma Health Sciences Center. Both of these projects have presented their work to the collaborative. Their presentations, Drs. Schaefer and Rogers participating in the national ad hoc work group on transition, and exploratory conversations with Healthy and Ready to Work programs in the Heartland and at the national center led us to take steps in addressing this issue in our region.

Given the states' disparate capacities to address this issue, our main objective this year is to increase the capacity through information sharing and identifying key partners and stakeholders for this issue.

- Objective 4: Increase states' capacity to implement pediatric to adult health care transition programs by May 31, 2009.
 - Activity 4-a: Identify the partners in the transition process from each state interested in developing a program.
 - Activity 4-b: Request technical assistance from HRTW National Resource Center via a webinar for the Heartland region.
 - Activity 4-c: Review and tailor selected, existing resources for specific states.
 - Activity 4-d: Disseminate resources via Heartland website and send to specific state partners.

Clinical Genetics Services Classification

Here is what we have to classify our Clinical Genetics Services. What is listed under Classification / Category are the headings from the form that went out to collect the info.

Classification / Category: [allows more than one to be selected]

General Genetics

- Geneticist on site
- Outreach Clinics

Oncology

- Hereditary Cancer Genetic Counseling

Maternal Fetal Medicine

- Maternal Fetal Medicine

Multidisciplinary Genetic Clinics

- Comprehensive Metabolic Clinic
- Down syndrome
- Fetal Alcohol syndrome
- Craniofacial
- Cystic Fibrosis Center
- Hemophilia and Bleeding Disorders
- Reproductive Endocrinology/Infertility Centers
- Other Multidisciplinary Clinic

Labs

- Cytogenetic Labs
- Molecular Labs
- Other Labs

Then, as in GeneTests, we can list Services Provided:

Adult Genetics

Pediatric Genetics

Prenatal Diagnosis

Cancer Genetics Counseling/Risk Assessment

Pre-implantation Diagnosis

Telemedicine

We need to decide on how to categorize these listings that makes the most sense. Do we use both? Do we need to give each type of multidisciplinary clinic a category, or will that be apparent in the clinic name? Please review for discussion.