

**Healthy Delawareans with Disabilities (HDWD)
Advisory Council Meeting
June 10, 2011
Center for Disabilities Studies, Newark, DE**

In attendance: Cory Nourie, Carol Barnett, Alex Eldreth, Al Rose, Tony Horstman, Ilka Riddle, Eileen Sparling, Dave Mills, Griff Campbell(via conference call), Harriet Ann Litwin, Kathy Stroh, Linda Gottfredson, Annalisa Ekbladh

Introductions

Approval of minutes- Minutes of the March meeting were approved.

The group reviewed the Advisory Council Meeting schedule for 2011/2012. Please note the new Dover location at Delaware Dept. of Transportation at 800 Bay Road.

FUNDING UPDATES AND OPPORTUNITIES

Awarded:

Domestic Violence – This project is a 3-year collaboration between the Center for Disabilities Studies (CDS), the Coalition Against Domestic Violence, and the National Alliance on Mental Illness (NAMI). Lead staff people are Kathie Herel at CDS, Lisa Becker at the Coalition, & Ken Singleton at NAMI. This project is funded through the US Dept. of Justice, Office of Violence Against Women.

Children and Youth with Special Health Care Needs (CYSHCN) Grant- The Division of Public Health received a grant to improve the system of services to CYSHCN (\$300,000 per year for 3 years). This will provide funding to Family SHADE, the Developmental Screening Project and Healthcare Transitions through CDS.

The Dental Alliance meets to address access to dental care and other dental issues for individual with disabilities. Adults do not get Medicaid coverage for dental care and legislative initiatives have not moved forward due to the economic situation. There has been no coordinated effort of needs assessment or data collection. Prof. Paul Solano of UD made a study proposal to interview dentists, talk with individuals with disabilities and perform a cost benefit analysis. Dr. McClure, Dental Director with the Division of Public Health, has committed \$100,000 to fund all pieces of the study over the next year. Dave Mills indicated personal interest in participating in the study. More details about the study will be discussed at a future HDWD meeting.

Proposals submitted and pending award decisions:

- **Leadership Education in Neurodevelopmental and related Disabilities (LEND)**
- **State Planning Grant to Improve Systems of Service to Children and Youth with Autism Spectrum Disorders**

Applications in process:

- CDS will be preparing a proposal for funding through the **Community Transformation Grant (CTG)** that the Division of Public Health will be submitting in July. CTG is a policy-based systems change grant. HDWD would provide technical assistance to other agencies to address the needs of individuals with disabilities and develop integration and inclusion

- policies. The CTG will help to inform HDWD on how to prepare for new CDC funding priorities. Eileen and Ilka are preparing an abstract for the DPH application for the CTG. BRFSS data shows individuals with disabilities underserved in areas addressed through CTG.
- CDS is preparing a proposal for the Developmental Disabilities Council to develop a **Training for YMCA Sports Staff and Volunteer Coaches on Inclusion of Youth with Disabilities**. This Training Grant will focus on an online training module for the 1500 volunteer coaches participating in Y activities each year.

Exit and Sustainability Plan – Eileen led a discussion of this draft plan. The group broke into teams to work on the Exit and Sustainability Plan.

Tony Horstman commented that individuals with disabilities do not understand the negative effects of smoking. State departments are wasting money in treatment and no prevention. Negative messaging does not work with individuals with disabilities.

Kathy Stroh commented that the same is true for diabetes. Negative messaging does not work.

Health promotion is not appropriate or targeted to individuals with disabilities. The Division of Public Health (DPH) is moving toward a prevention model. DPH is required to use evidence-based models which are not appropriate for individuals with disabilities and many other populations.

Status of the **Office on Health Equity**: Eileen and Ilka met with Rita Landgraf, Secy. of Health and Social Services, and Dr. Karyl Ratty, Director of the Division of Public Health. The Division of Public Health feels that the Office is a good idea. Establishing an Office of Health Equity is under active consideration.

PARTNER UPDATES

Al Rose – Developmental Disabilities Council is working on a bill for universal design. It was just sent to the House lawyer for review. The bill will require a “points” scale for developers, providing points given for elements of universal design.

Prof. Linda Gottfredson – Linda is working with Division of Public Health and CDS on a project to create cognitively accessible instruction for diabetes self-management for individuals with disabilities. She is working now on a provider survey with a rating scale for diabetes self-management tasks. There will be pilot testing of the survey to providers. There are also plans for doing focus groups with individuals with disabilities and caregivers to identify their greatest challenges. Delaware is the only state looking at this issue. They will be seeking funding to develop the training. Please contact Linda with ideas for contacting patients.

Cory Nourie - Al Dupont Hospital received a grant from NYMAC. Dr. LaComte is working on care guidance in the areas of Sickle Cell, O.I, Spina Bifida, and Diabetes.

Tony Horstman – Asked a question about the lack of a clinic for adults with Down Syndrome.

Next Meeting: Friday, September 9, 2011 at 10:00 a.m. at Delaware Dept. of Transportation Administration Building, Farmington-Felton Room, 800 Bay Road in Dover.