

Healthy Delawareans with Disabilities

Friday, December 11, 2009

10:00am-12:00pm

Delaware Biotechnology Institute, University of Delaware

15 Innovation Drive, Room 102

Newark, DE 19711

(302) 831-4888

MINUTES

Present: Michelle Eichinger, Al Rose, Jane Miller, Nancy Ranalli, Jerry Gallucci, Marianne Carter, Chris Oakes, Linda Gottfredson, Harriet Ann Litwin, Marie Eldreth, Leila D. Perkins, Vicky Tosh-Morelli, Joya Asika, Paulette Smith, Kathy Stroh, Carol Barnett, Ilka Riddle, Eileen Sparling, Terri Hancharick, Sharon Romelczyk, Paul Galonsky, Ally Tworkoski

Welcome / Approval of Minutes

The group reviewed and approved the minutes from the September 11, 2009 meeting.

HDWD Program Updates

Strategic Plan

Ilka Riddle announced that 105 copies of the Strategic Plan were distributed to AC members and friends to date. In the new year, meetings will be set up with key stakeholders, including division directors and Secretary Landgraf to talk about the plan. The goal will be to summarize the goals and objectives each stakeholder can adopt or address. Implementation of objectives and actions will take place over the next two years, and beyond.

Some objectives for year four include accessibility of health care facilities and recreation opportunities, medical transition and evaluating facilities. Members commented about how great the strategic plan looks.

Ilka thanked everyone for their help and input to the Strategic Plan.

H1N1 Update

HDWD, in collaboration with the Division of Public Health (DPH), held an H1N1 information session on Nov 3 at CDS. Twenty-five community members attended. School nurses were concerned because they felt the children in their schools were falling through the cracks because they couldn't get the flu mist. To promote this event, Ilka participated in a radio interview on WILM with DPH staff member, Dr. Paul Silverman.

New information was added to the website, including anew brochure for parents with special health care needs and disabilities. DPH set up three clinics across

the state in November and December. The clinics were well-organized, very accessible, signs were bi-lingual, and sign language interpreters were available.

Transition

Terri Hancharick spoke about the Healthy Transition trainings for parents and caregivers and youth with disabilities that she conducted at CDS. There were separate trainings for parents/caregivers and for youth and young adults. Fifteen families participated. There were great friendships made between families, and lots of sharing information. Family 2 Family, Practice without Pressure and medical transition staff were involved in presenting at the workshop.

Staff is hoping to continue trainings in Kent and Sussex. Families indicated that they hope there will be another one. Terri has applied for additional funding but hasn't heard yet if we got it or not.

Funding Opportunities

CDC

The CDC re-application was submitted in early December.

Emergency Preparedness

We received an Emergency Preparedness (EP) Grant. This grant allows us to hire a part-time coordinator who will work with Emergency Preparedness for Individuals with Non-Typical Functional needs. The goal is to help individuals with disabilities and family members get involved in the EP planning process, and to ensure that state planning integrates the needs all groups of people (elderly, disabilities, bi-lingual, immigrants, Amish). It is a one-year planning grant received jointly with the Inclusive Preparedness Center. The plan calls for regional involvement (PA, NJ, V, WV, MD, NC). This grant is a good opportunity to move EP planning forward in the state.

Family Support Initiative

The center received a Family Support Initiative Grant through the Office of Children with Special Health Needs at DPH. This will allow the center to oversee all of the groups, find out their strengths, and to encourage collaboration. Program coordinator will start in January.

Health Summit Grant

This is a proposal to fund a conference on health and disability issues in Delaware. We originally applied in early 2009 and didn't receive funding. The funding opportunity was reissued and we submitted a revised application. If we do not receive funding, we will still plan for a scaled-back health summit in March of 2011 to raise issue around people with disabilities and health.

Healthy Relationships

We are exploring an RFP for a project around healthy relationships and people

with disabilities. We submitted a letter of intent, and a bid call will take place next week to see if we qualify for it. Application is due January 6th.

Transition clinic

The Transition Clinic at A.I. DuPont Hospital informally opened in November and will officially open in January. CDS will complete an evaluation to assess need for the clinic, satisfaction with the program and to identify future program expansion opportunities

Alliance on Oral Health

The Alliance on Oral Health finalized its mission and vision and is currently drafting a work plan of goals regarding oral health in Delaware, including legislative efforts, and community education on good oral health behaviors. House bill 359 would have brought Medicaid funding for dental care for adults with disabilities but that did not pass. The group has been in contact with Senator Hall-Long to discuss feasibility and interest in re-introducing the bill.

Medical database

The center received a new contract from the Developmental Disabilities Council to develop a medical database. This project will involve surveying physicians, dentists and mental health professionals about their practice accessibility and experience working with people with disabilities. The project will develop an online database that people can search to identify providers that may be available to them after they transition out of pediatric care.

Prosthetic Parity Bill

Paul reported that he provided technical assistance to the prosthetic parity coalition so a bill could be introduced in the next legislative session. Insurance companies put caps on prosthetics and the coalition wants to address this. Gloria Price, from the Amputee Support Group of Delaware, and an HDWD Advisory Council member, is in touch with Helene and Gerald Brady, two legislators were very interested in developing a bill, and shared a model bill from Rhode Island. To date technical assistance has included help in writing letters to legislators, drafting recruitment letters to build the coalition in the state, and meeting support for meetings held at CDS.

Women's Health Projects

Sharon Romelczyk presented on the Delaware Mammography Accessibility Project. Eileen stated that screening rates for women with disabilities nationally show that Delaware is at the very top of the list. The Cancer Consortium has done great work in getting this done. All facilities need to be accessible for all individuals. Sharon presented the AUCD conference DMAP poster to the group.

Recreation

Terri informed members that the recreation group and partners are working on accessibility of state parks. A donation of accessible bike was made in May. The group is contacting Rehoboth to help improve access for wheelchairs onto the beach so people with mobility issues can get to the water- (mobimat). HDWD would like to sponsor a day in the state parks to promote accessibility - one in each county where people from all different recreation areas will set up tables with exhibits and show what they have for outdoor enjoyment and classes.

Autism Delaware is working on a project called "Rec4All" developing a collaborative calendar to send out to people to let them know about accessible events.

2008 BRFSS Report

Paul presented on the Behavioral Risk Factor Surveillance System (BRFSS) report that HDWD generated. HDWD was charged by CDC with reporting specifically disability and health in Delaware. This report explores differences in health status between individuals with disabilities and those without disabilities. All secondary health conditions are higher for people with disabilities. The BRFSS data has some limitations. Comprised of telephone surveys to adults 18 years or older, the survey doesn't collect data from people in institutional settings, people who may use assistive listening devices, or people who don't have a land line telephone. Michelle Eichinger (DPH) reported that there is going to be a big shift on how data is collected. Concerns about sampling are already on their radar and there is going to be a change in data collection. The report will be on the website in January.

Updates from Partners

Aging and Disabilities Resource Center

Chris Oakes from Division of Services for Aging and People with Physical Disabilities (DSAPPD) gave a presentation on the Aging and Disabilities Resource Center. DSAPPD has received funding for this program. They serve individuals of ALL income levels. The core functions of this program are: info and awareness, options and counseling, streamlined access to public programs, person centered hospital discharge planning, and quality assurance.

The Governor's Advisory Council will provide Technical Assistance.

Since October Chris has been involved with development and management of the project, met with lead partners, advisory council. She encourages everyone to join in on their webinars- at site locations (Milford, NC, Easter Seals), or from home computer.

Easter Seals

Nancy Ranalli from Easter Seals invited everyone to visit the facilities newly expanded resource center. Send her an email to set up a time to come over.

They have a meeting room available for use, an (satellite site) office with a computer, and a large conference room, no charge.

Practice without Pressure

Jane Miller from Practice without Pressure (PWP) reported that PWP has the first practice procedure center, up and running, and they now have dental equipment operational. Everyone is welcome to set up a tour or presentation at the facility.

Developmental Disabilities Council

Al Rose announced that the LIFE conference price is low until January 5th. He also announced that recruitment for Partners in Policymaking is going on. Meetings are held one weekend a month for eight months. It is a great opportunity to connect with other people who have similar situations and to learn about all of the services in Delaware.

DSAPPD

Carol Barnett is updating a guide to services – a comprehensive guide that encompasses both services for those who are older and services for adults who have disabilities. Let her know if she has missed any resources throughout the state.

Wrap Up & Adjournment

Eileen announced that this is Paul Galonsky's last meeting. He received a policy fellowship working in Washington working with the Association of University Centers on Disabilities. We thank him for all of his hard work and wish him all the best.

**Next Advisory Council Meeting Friday, March 12, 2010, 10:00 am -12:00 pm,
Location TBD**