Governor's Advisory Council for Exceptional Citizens (GACEC)

State Task Force for Centralizing Internet Resources for Children with Disabilities and Special Health Care Needs (HCR 31) Meeting
Tuesday, October 29, 2013 ~ 2:00 PM to 4:00 PM
George Massey Station, 2nd Floor Conference Room
516 West Loockerman Street, Dover, DE   19904

Attendees: Wendy Strauss/GACEC Executive Director & taskforce co-chair, Terri Hancharick/GACEC Chairperson & taskforce co-chair, Pam Reuther/Easter Seals and Family SHADE Board member, Mary Sonnenberg/Delaware Stars, Cindi Wood/Developmental Disabilities Council, Kim Siegel/Autism Delaware, Heidi Mizell/Autism Delaware and Family SHADE Board member, Jack Jadach/former principal-Leach School, Ron Russo/GACEC, Carmen Gallagher/Early Childhood Council & Parents as Teachers, Phyllis Guinivan/Family SHADE staff & Center for Disabilities Studies, Annalisa Ekbladh/Family SHADE staff & Center for Disabilities Studies, Marissa Band/Disabilities Law Program, Kristin Wilson/Child Development Watch, Shawn Rohe/Parent Advocate, Ann Phillips/Delaware Family Voices & Family SHADE, April Hill-Addison/Delaware Head Start, Cory Nourie/A.I. DuPont Hospital and Family SHADE, Brigitte Hancharick/self-advocate, Sybil White/Parent Advocate, Kristin Cosden/GACEC staff and Kathie Cherry/GACEC staff. On the phone were Dr. Heather Alford of the Division of Family Services and Bhavana Viswanathan of the Division of Public Health.

Wendy Strauss called the meeting to order and welcomed attendees. This Task Force has been called together to look at early childhood resources in Delaware and determine if there is a need for a website. It was mentioned that other organizations and individuals have been invited to be a part of this stakeholder group who are not in attendance today. We hope to get input from them as we progress. Additionally, there are individuals who have been invited to be a part of the group who are not listed in the legislation but have information to share that may be helpful. This group will discuss where the gaps in information are, discuss what needs to be done, discuss anticipated outcomes and develop a report to be given to the Governor in June of 2014.

Phyllis Guinivan opened the discussion with information on the Family SHADE website which began three years ago as a project with the Division of Public Health. A stakeholder group was formed at that time to discuss the development of their website. The Family SHADE website has an information referral center which provides one on one conversation with parent representatives, mobile applications and a database housed at Children and Families First which goes across the lifespan. This website is grant funded through Title 5.

A question was asked on how long those grant funds will last and the response was that one section of the grants will end in 2014 so additional funds will have to be secured to continue the website.

Additional comments were made on working towards enhancing or augmenting the work that is already in place rather than working towards the establishment of another website.

Background was provided on the passage of the legislation which has led to this Taskforce and what was discussed to get us to this point. It was mentioned that there is a need to gather information into one centralized, parent-friendly location and connect to websites that are already available. Parents do not want to have to contact more than one entity. They want to make one phone call and be connected to all of the information they need. It was mentioned that we need to develop a way to categorize resources from all sources in order to make information more accessible for parents.

The Help Me Grow and 2-1-1 programs were discussed in terms of connections to websites that are already up and running in addition to information that will be available on the Family SHADE website in 2014, such as the Road Maps. Comments were made about agencies and organizations being unwilling to collaborate due to fear of loss of funding and territoriality.

A comment was made that the legislators who sponsored the legislation may not be aware that there is a one stop website already available and that it should be considered wasteful spending to reinvent what is already available rather than using funds to enhance the current one stop under Family SHADE.

A suggestion was made to invite tech people to be at the table from the beginning in order to gather their perspective from the beginning. It was also mentioned that careful attention needs to be paid to marketing and naming of websites.

Sustainability was mentioned several times. Wendy discussed the Memorandum of Agreements that several of the Cabinet Secretaries have agreed to sign to ensure sustainability of the upcoming website recommended by the Transition task force. The Department of Technology and Information (DTI) has been meeting with members of the Transition task force to get the Transition website up and running as soon as possible. DTI representatives will be invited to meet with this group once more information has been agreed upon.

Continuing discussion focused on the infrastructure that the Family SHADE website already has and the cooperation of the more than 40 organizations that have joined efforts on the Family SHADE website. The Road Map, which is scheduled to be rolled out in 2014, is based on a Georgia website design. It was mentioned that the Center for Disabilities Studies (CDS) had planned to roll out a new website several years ago but it never came to fruition. That group met several times and had planned to use The Road Map format, similar to the Georgia format as well but the effort ended before the website could be developed. There are several other groups who are currently developing new websites or enhancing their current sites. It was reiterated that this website could be a conduit to those sites.

It was clarified that the funds that were mentioned as already given for a website were given to the GACEC for the Transition website, not the website proposed by House Concurrent Resolution (HCR) 31. Since there are no dedicated funds for another website, it was suggested that it makes more sense to collaborate and enhance current websites. It was mentioned that a fiscal note will have

to be a part of the report that is given by this Taskforce in June. A suggestion was made to secure additional funding for the Family SHADE website since the current grant funds are running out.

Discussion ensued on the compartmentalization of needs based on age. Information was provided on the age range for the Family SHADE website, the Delaware Aging and Disability Resource Center (ADRC) website and HCR 31 legislation. Questions were asked on why the legislation to develop an early childhood website lists the age range from prenatal to age 13 when early childhood typically stops at age eight. Transition begins at age 14 so the legislation sponsors wanted a smooth transition from prenatal services to age 13 with the early childhood website and then from age 14 to 30 on the Transition website.

Clarification was given on the reason for this Taskforce as outlined in HCR 31. This group has been established to 1) study the needs of children with disabilities and special health care needs from diagnosis to age 13; 2) gather information and 3) recommend resources for a single master website for use by families of children with disabilities and special health care needs and other interested parties.

It was suggested that individuals working with the early childhood community should review the Family SHADE website in order to come up with recommendations on things that are missing from the site. Discussion continued on data collection on site usage. Family SHADE collects data using Google Analytics and will share their data with the group. It has shown that the upcoming events and database information sections are accessed the most. Google Analytics is also able to track information on where the user goes next.

It was decided that stakeholders will explore the Family SHADE website and other resources they currently use or are aware of prior to the November 21 meeting in order to determine what is missing and what other resources need to be included on an early childhood website. If information on other available resources is submitted prior to the meeting, it can be disseminated to the whole group. It was also suggested that internet accessibility be provided at the November meeting so the group can look at various sites. A comment was made about the fact that several of the current systems are not able to 'talk' to each other.

Comments were made on continuing to switch between morning and afternoon meetings in order to accommodate various work and teaching schedules. It was also noted that participants should be mindful that some websites may be good resources but may not be very parent-friendly. Too much information or too much technical information may be overwhelming for parents. A response was made that parents should be allowed to determine what is too technical for themselves.

The next meeting will take place on November 21 in the George Massey Station 2nd floor conference room from 9a.m. to 11a.m. Participants are expected to review various Delaware early childhood websites and resources, including the Family SHADE website to determine what is needed and what is missing. Information on resources can be sent to the GACEC at Kathie.cherry@gacec.k12.de.us for dissemination to the entire group prior to the November 21 meeting. Visual aids will be provided to assist with categorization and internet access will be provided.

Wendy thanked everyone for attending and the meeting was adjourned at 3:40p.m.