Parent Partners in Health Education Update

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Parent Partners in Health Education (PPHE) is a curriculum to train medical residents about working with families and individuals with developmental disabilities. Funding for PPHE projects is provided by the NYS Developmental Disabilities Planning Council (DDPC). The NYS Council on Graduate Medical Education (COGME), provides technical assistance to PPHE grantees and is conducting the overall program evaluation of the grants. The PPHE Update is to inform you about this important project and to share information that may be used in your residency program. (Please note that no additional projects are being funded at this time.)

If you would like to share information about your educational activities related to developmental disabilities, please contact us.
Thomas Burke, Executive Director, COGME
Gloria Winn, PPHE Coordinator
COGME, Corning Tower Rm 1190, Empire State Plaza, Albany, NY 12237. 518-473-3513.
gme@health.state.ny.us

Adults with developmental disabilities need primary care and OB/GYN services

Advocacy groups representing adults with developmental disabilities assert that their constituency faces many barriers to quality health care, often because physicians are not trained to meet their needs. They cite these facts in support of their call for more training of primary care providers for individuals with developmental disabilities:

- The life expectancy for individuals with developmental disabilities has increased from 20 years in the 1930s to 60 years in the 1980s. Current estimates suggest that between 600,000 and 1.6 million Americans over the age of 60 are individuals with developmental disabilities. The number is expected to multiply to several million by 2020.

- The 6th Annual Developmental Disabilities Conference for Health Professionals (San Francisco, March 2007) reported that people with intellectual disabilities are 4 to 6 times at higher risk of dying from preventable causes than the general population.

- Internist respondents to a 2002 California survey revealed that only 25 percent received disability-related education in medical school and 28.7 percent received some training in residency. When asked if such training would have been helpful, 56 percent said yes. Over 77 percent felt there is a current need for training.

It is reported that more than 10 million women in the U.S. are limited by some type of disabling condition, including developmental disabilities. In addition to primary care, they need routine OB/GYN services.

Many OB/GYN practitioners also serve as primary care practitioners. These two studies give support to the concern that more training is needed by medical professionals:

- OB/GYN physician respondents to a 2002 California survey revealed that only 10.4 percent received disability-related education in medical school and 20.3 percent received some training in residency. When asked if such training would have been helpful, 31 percent said yes. Fifty percent felt there is a current need for additional training.

- A 2004 study of women with developmental disabilities in North Carolina found them significantly less likely to have had routine breast and cervical screening than women without disabilities.

A variety of reasons are cited to explain the lack of residency program training to prepare primary care physicians to care for adults with developmental disabilities: residency programs already stretched to meet RRC requirements; reluctance to add more time to residency training; increased interest in specialization rather than primary care; and inadequate attention to developmental disabilities in medical schools. The result, however, is suboptimum health care for this population.

PPHE family medicine residencies working with adults with developmental disabilities

DDPC's Parent Partners in Health Education (PPHE) initiative includes five grants to family medicine residency programs to integrate the PPHE curriculum, which focuses on families and children/adults with developmental disabilities, into their ongoing residency curriculum. The curriculum includes didactic lectures, home visits to families or group home settings, community agency visits, clinical experiences, medicine case presentations, small discussion groups, and reflection logs. While all programs meet the same RRC requirements, they have used different strategies to incorporate the PPHE curriculum. These project have found that the PPHE fulfills many RRC requirements.

- Didactic lectures and medicine care presentations are offered at Grand Rounds, Noon Conferences, or designated time for PPHE activities. The required lecture topics, including an orientation to PPHE, are Assessment of Developmental Disabilities (Denver II for children), Legal Aspects and Assessing Services, and Doctor-Patient-Family Communications.

- Residency programs may emphasize pediatrics, adults, or both. When possible, each resident is paired with a patient from the continuity clinic, insuring continued clinical contacts. Residents then visit the home or congregate living home to learn more about the daily lives of families or the adult, learn about the medical and support services provided, and become familiar with the individuals and agencies working with the individual.

- Most home visits are made with a social worker or other professional. A single resident or a small group of residents may participate in a home visit. Home and agency visits may be made during a rotation such as a pediatric or community medicine rotation, or sometimes during continuity clinic time. One residency program has a one month orientation to family medicine during which some of the PPHE lectures are given and home and community agency visits made.

Accommodations to successfully add PPHE are not difficult although they do require careful thought. Initial PPHE program evaluation data allows some insight into the residents' experiences with PPHE. The residents report satisfaction in getting to know individuals personally, in ways that are not possible in routine office visits. They become comfortable interacting with the families and the individuals with developmental disabilities and have expressed interest in learning more than what is included in the curriculum. They also report increased confidence in their clinical skills.

Moreover, families express satisfaction at helping the residents learn about their home lives and the impact of having a child or adult with a disability. Group home care team members and agency health care providers appreciate resident involvement in team planning.

Report on PPHE Phase I Projects available

COGME has issued a report on the experience of the four grantees who implemented the PPHE curriculum as part of their residency programs in pediatrics and/or family medicine between 2005 and 2008. St. Barnabas Hospital (Bronx), St. Elizabeth Medical Center (Utica), Stony Brook University Hospital, (Stony Brook), and Winthrop University Hospital (Mineola) each had three year grants from the DDPC to implement and evaluate the curriculum. Copies may be requested from COGME.

Westchester Institute of Human Development dental van travels to meet need

The Westchester Institute of Human Development (WIHD) operates a Dental Van that travels to group homes throughout the county to treat mentally and physically disabled patients, including some with very poor oral health due to an inability to brush or floss on their own. The van has room for a dental chair, electric examination tools and a tray of supplies to use to treat patients. They are able to perform routine checkups, cleanings, tooth fillings and minor extractions.

The van has been in operation since 2006 travelling to 10 sites from Yonkers to Millbrook and treats 2000 patients regularly. The van fulfills a great need for these communities due to the difficulty in finding dentists willing to take Medicaid who are also trained to treat special-needs patients.

About 2,600 dentists in New York actively treat Medicaid patients, according to the NYS Health Department's Web site. Only a fraction of the dentists who accept Medicaid are able to treat special-needs patients. The NYS Office of Mental Retardation and Developmental Disabilities reports that there are 140,000 developmentally disabled people on Medicaid in New York. (Reported in NYS DDPC's Ebulletin September 2008)

AAP makes oral health training available

The American Academy of Pediatrics offers access to a curriculum on **Special Care: An Oral Health Professional's Guide to Serving Young Children with Special Health Care Needs**. This series is designed to provide oral health professionals with information to help ensure that young children with special health care needs have access to health promotion and disease prevention services that address their unique oral health needs in a comprehensive, family-centered, and community based manner.

The five modules are: Module 1: An Overview of Children with Special Health Care Needs and Oral Health, Module 2: Providing Optimal Oral Health Care, Module 3: Oral Health Supervision, Module 4: Prevention of Oral Disease, and Module 5: Behavior Guidance. Each module is followed by a bibliography and a list of resource organizations.

The web site for the oral health guide is: www.aap.org/commpeds/dochs/oralhealth/training.cfm

Commonwealth report on developmental screening in primary care available

A recent Commonwealth Fund report summarizes research on the effectiveness of current efforts by primary care health professionals to detect developmental delays in early childhood and considers ways to improve outcomes for young children and families. *Developmental Screening in Primary Care: The Effectiveness of Current Practices and Recommendations for Improvement* reports the prevalence of developmental delays is at least 10 percent but early intervention programs aimed at addressing these concerns serve only 2.3 percent of children under age 3. The author, Laura Sices of Boston Medical Center/Boston University School of Medicine, urges strengthened developmental surveillance and screening.

The Commonwealth report is available at: www.commonwealthfund.org/usr_doc/1082_Sices_developmental_screening_primary_care.pdf?section+4039.

What the British are doing to assess developmental milestones in kids

According to Cox News, Great Britain has instituted a new law, effective September 2008, to enforce the mandatory evaluation of children's learning and development from birth through age 5. The Early Years Foundation Stage (EYFS) is the framework that sets up 69 early learning goals, using 500 developmental milestones, which are to be used by all day care providers and child minders to determine if a child is progressing appropriately.

The six areas covered by the early learning goals and educational programs are: Personal, social, and emotional development; communication, language and literacy; problem solving, reasoning and numeracy; knowledge and understanding of the world; physical development; and creative development. It is expected that all adults who interact with the child, including nannies, nurseries, parents, and schools will contribute to the evaluation process.

Increase in autism diagnosis spurs new programs

An increase in autism diagnoses has been the most significant trend in the treatment of developmental disabilities in New York over the past two decades, according to state mental health officials. There has been a 350 percent increase in those with an autism or autism spectrum disorder among those served by the NYS Office of Mental Retardation and Developmental Disabilities (OMRDD). Fourteen percent of the agency's clients have autism, compared to three percent in 1989. At the same time, the percentage of clients diagnosed as mentally retarded has dropped to 85 percent from 95 percent in 1989. Crain's New York Business Report (September 3, 2008) reported that New York ranks 22nd in the prevalence of autism among school children, while New Jersey ranks fourth.

OMRDD has created a New York State Autism Consortium under the leadership of their research arm, the Institute for Basic Research in Developmental Disabilities. The consortium will involve the state/s finest scientific minds to collectively research, treat and address autism and autism related disorders.

In July 2008, Governor Patterson signed a bill that required the Department of Health to update the guidelines used by pediatricians to identify children with Autism Spectrum Disorders and refer them to appropriate services. OMRDD supports more than 16,000 people in New York State with autism or autism spectrum disorders and anticipates that in the next decade autism could impact an estimated four million Americans.

New 100 day kit helps families cope with a diagnosis of autism in a child

A new downloadable publication from Autism Speaks is designed to help families who have just received a diagnosis of autism for their child make use of the next 100 days to understand the condition and deal with issues such as getting services and interventions. The intent of the publication is to provide general information about autism as a service to the community.

The website for the Autism Speaks kit is www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf

OMRDD gets Fragile X Grant

The research institute of the New York State Office of Mental Retardation and Developmental Disabilities was awarded a nearly $1.6 million, three-year cooperative agreement grant from the CDC's National Center on Birth Defects and Developmental Disabilities. The funding is for research on Fragile X Syndrome, which causes mental retardation in boys and is the most common single-gene cause of autism. About 4,000 male New Yorkers have Fragile X Syndrome, and 1 in 250 women are carriers of the sex-linked condition. The Staten Island-based Institute for Basic Research in Developmental Disabilities is one of 14 clinics nationally that research Fragile X. (Reported in Crain's New York Business, September 19, 2008)

DDPC awards two grants on Fetal Alcohol Spectrum Disorders

The NYS DDPC has awarded a $75,000 grant to the American College of Obstetricians and Gynecologists District II/ NY (ACOG) and $29,341 to the Research Foundation of State University of New York to help prevent Fetal Alcohol Spectrum Disorders (FASD). FASD describe a range of birth defects resulting from prenatal alcohol exposure and characterized by physical, behavioral, and/or learning disabilities. An estimated 1 in 100 newborns are affected and nationally as many as 40,000 babies are born with FASD every year.

ACOG will develop a FASD educational toolkit to educate women of childbearing age about the dangers of alcohol use during pregnancy and offer methods to prevent FASD. ACOG plans to distribute 6,000 patient education toolkits to ACOG members, medical associations, relevant organization, and public. The Research Foundation of SUNY will develop four one-day workshops on FASD to provide an overview of FASD, including practice strategies and referrals, for medical professionals.

DDPC E-bulletin subscription drive

The Developmental Disabilities Planning Council is looking for new subscribers for its very informative monthly E-Bulletin. All you have to do is go to the sign up sheet. Once you submit the form, you will receive an email from DDPC to confirm your request. You then reconfirm by clicking the "Yes I Want to Join" link.