



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.

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PPHE presentation at STFM

Samuel Sandowski, MD, Director of the Family Medicine Residency Program and the PPHE Project Director at South Nassau Communities Hospital, Oceanside, presented "Developing a Curriculum in Caring for Children with Developmental Disabilities" at the fall 2008 STFM NorthEast Region meeting in Baltimore. The presentation on the PPHE curriculum fit well with the conference theme, The New Deal in Healthcare: A Medical Home for All.

Dr. Sandowski's grant, now in its second year, has several unique features. 1. All family medicine residency program faculty participate in PPHE along with the residents. This ensures that the faculty clearly understands what the residents are learning. 2. South Nassau Communities Hospital partnered with the United Cerebral Palsy Association of Nassau County (UCPN) to provide clinical experiences (including a one week rotation) and didactic lectures for the PPHE program. 3. The hospital and UCPN collaborated on a day-long symposium (5 hours of CME) last June, "Caring for Children with Developmental Disabilities." The symposium was open to residents and physicians in Long Island and nearby boroughs. 4. Next year, Dr. Sandowski plans to expand the number of didactic lectures to include autism, attention deficit and to offer more detailed information on early intervention and support systems.

Partnering with community agencies

Developing close working relationships with community service agencies offers benefits to both the agency and a residency program. The PPHE curriculum presents an excellent opportunity to enrich these relationships.

- The Institute for Urban Family Health in New York City has established a strong relationship with the New York Association for the Help of Retarded Children to provide didactic lectures and clinical experiences. Dr. Andreas Cohrssen, the Institute's Family Medicine Residency Director and the PPHE project director, has blended much of their PPHE program into their one month fall orientation program.

- St. Elizabeth's Family Medicine Residency program, Utica, involved agencies in a Community Partners Group, which collaborated on a community needs assessment prior to starting PPHE and subsequently assisted in recruiting parent partners and arranging home and agency visits.

- St. Barnabas Hospital Pediatric and Family Medicine Residency programs, Bronx, under the

direction of developmental pediatrician Dr. Paola Carugno, involved visiting nurses from St. Mary's Hospital for Children to provide residents with their first home visit. The visiting nurses served as models for professional behavior and were able to guide discussion of family issues after the visit.

Psychiatry residents participate in PPHE

The PPHE curriculum has been used in physical medicine and rehabilitation, pediatric, and family medicine residency programs. Dr. Nienke Dosa, PPHE program director at SUNY-Upstate, Syracuse, is reaffirming the flexibility of the PPHE curriculum by including psychiatry residents in her program for pediatric residents this year (2008-2009). The didactic lectures (especially on legal issues and accessing services), community agency visits (particularly, early intervention program and school visits), and clinical experiences with individuals with developmental disabilities are particularly relevant to psychiatry.

The 15 minute mental health visit

The AAP Task Force on Mental Health, in collaboration with several national groups, conducted a teleconference for primary care providers on how to approach mental health concerns with parents, children and adolescents in the primary care setting. Larry Wissow, MD, MPH and Anne Gadomski, MD, MPH discussed the "common factors" approach and presented video clips of doctors interviewing simulated patients with frequently seen mental health problems. The 15 Minute Mental Health Visit Web-Based Teleconference Recording is available at www.aap.org/mentalhealth under Children's Mental Health News.

PPHE in the SUNY-Stony Brook School of Medicine

Dr. John Pomeroy, Director of the Cody Center for Autism and Developmental Disabilities and an active leader in Stony Brook's PPHE grant (2005-2008), is incorporating elements of the PPHE curriculum into the developmental disabilities portion of the School of Medicine's psychiatry in medicine, which was designed by Peter Halperin, MD. First year medical students have a full day's introduction to developmental disabilities, including a lecture on the history of care for individuals with developmental disabilities in the U.S., general information, and

erroneous assumptions. Fourth year medical students meet with Dr. Pomeroy and parents of individuals with disabilities to learn about daily life and family issues. After the parents present as a panel, parents join the medical students for lunch (pizza, of course) to answer questions one-to-one.

Reflections and narrative medicine integrate learning

Residents participating in PPHE are asked to write reflections on their home and agency visits, as well as on any PPHE experiences they find interesting. Although some residents grumble at the extra writing, many find it useful in gaining perspective on their experiences as related to future clinical practice. Dr. Heidi Beutler, PPHE project director at the Morgan Stanley Children's Hospital of New York Presbyterian, has added a variation – narrative writing – to augment small group sessions where residents talk about their PPHE experiences. Residents describing their home visit are given a few minutes to write a brief story from the patient's (or parent's) point of view. Other residents may then question "the patient or parent."

David Leach, MD, former executive director of the ACGME, said in support of reflections: "As residents try to make sense out of their experiences they use conversations with peers, with faculty, with nurses, with anybody to clarify what has actually happened. Journaling helps; recalling specific events of the day can consolidate the lessons of the day. Most residents lack time for formal reflection. However, its importance makes it a top priority, eventually resulting in reflection-in-action with its attendant time- and quality-saving features."*

- * Leach, D. Using Assessment for Improvement: It Begins with Experience. ACGME Bulletin, April 2006, page 4.
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Office of Mental Health starts electronic newsletter

The New York State Office of Mental Health has started an electronic newsletter, [OMH News](http://www.omh.ny.gov). This monthly publication will provide articles and information for people who are served by, working, involved or interested in New York State's public mental health system. The OMH Newsletter link is located in the left-hand column of the OMH Internet Webpage, www.omh.ny.gov.

Escape DVD

The NYS Developmental Disabilities Planning Council has available an abuse prevention training curriculum developed collaboratively by Teacher's College, Columbia University and A HRC of New York City. This training package, "Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment for Adults with Developmental Disabilities" (ESCAPE-DD), includes a CD of training resource materials and a DVD of training scenarios intended to be used with people with developmental disabilities to help them identify, avoid, and effectively respond to potentially abusing situation and/or relationships. To obtain a free copy, contact DDPC at 518-486-7505 or contact nrose@ddpc.state.ny.us.

FASD prevention resources

FASD (Fetal Alcohol Spectrum Disorders) is a range of conditions that includes physical, mental, behavioral, and/or learning disabilities. It is important to know that FASD can occur when a woman drinks at any point during pregnancy and there is no "safe" amount of alcohol that can be consumed. FASD is also the only fully preventable cause of birth defects. For more information about this spectrum of disorders, see:

- The www.fascenter.samhsa.gov/ FASD Center for Excellence is a federally funded initiative devoted to preventing and addressing FASD.
- The Substance Abuse and Mental Health Services Administration in the U.S. Department of Health and Human Services has several ongoing FASD Initiatives.
- CDC addresses fetal alcohol syndrome (FAS) through the activities of its National Center on Birth Defects and Developmental Disabilities (NCBDDD) www.cdc.gov/ncbddd/fas/
- NIAAA (National Institute on Alcohol Abuse and Alcoholism) supports research leading to improved diagnosis and assessment of impairment and disability, as well as the development of tools to enhance academic and daily living skills. NIAAA also hosts the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS).

- Division of Perinatal Systems and Women's Health of the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau conducts activities related to FAS prevention.

- New York State Office of Alcoholism and Substance Abuse Services website is www.oasas.ny.gov/fasd/index.cfm

New York State resources for children with special health care needs

Seventeen state programs for children with special health care needs are described in detail at www.health.ny.gov/community/special_needs/resource_directory.htm Services and eligibility requirements are described for programs, such as home Medicaid Waiver, Child Health Plus, Early Intervention, Community-Based Services, Medicaid, Special Education, and Supplemental Security Income.

Statistics on disabled Americans

According to Census Bureau data for the Americans with Disabilities Act (2005), 37.5 million American over age 5 have at least one disability. The data does not specify developmental disabilities, although these diagnoses are included. The numbers below represents people age 5 and older; the percentages refer to the civilian noninstitutionalized population age 5 and older.

- 10.8 million people (4.1%) have a sensory disability involving sight or hearing.
 - 23.6 million people (9%) have a condition limiting basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying.
 - 13.5 million people (5.1%) have a physical, mental or emotional condition causing difficulty in learning, remembering, or concentrating.
 - 7.0 million people (2.7%) have a physical, mental, or emotional condition causing difficulty in dressing, bathing or moving around inside the home.
 - 10.7 million people (4.9%) have a condition that makes it difficult to go outside the home to shop or visit a doctor.
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