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. 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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By the numbers

Telling a story with just numbers overlooks the inherent value and worth of the individuals being counted. Yet, the numbers are impressive: 17% of children in the U.S. are estimated to have a developmental disability. The prevalence of individual disabilities ranges from 0.2% for cerebral palsy to 6.5% for learning disabilities. These conditions have a substantial impact on the health and educational functioning of affected children: 1.5 times more doctor visits, 3.5 times more hospital-days, twice the number of school days lost, and a 2.5 fold increase in the likelihood of repeating a grade in school compared to children without these conditions. (Ref: Boyle C, Decoufle PM, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. Pediatrics, 1994 Mar; 93(3): 399-403.)

Moreover, 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.
(Ref: American Association on Intellectual and Developmental Disabilities, Accessed 5/27/08 http://www.aaidd.org/content_181.cfm)

These numbers dictate that most primary care providers- and many medical specialists- will encounter individuals with developmental disabilities in their practices. Resident training on working with families and individuals with developmental disabilities is important for honing skills essential to the quality of medical care these individuals deserve.

PPHE adds to Stony Brook School of Medicine psychiatry course

Stony Brook School of Medicine has a required fourth-year psychiatry course consisting of 17 clinically relevant seminars on psychiatric issues often seen in out-patient settings, including topics related to developmental disabilities. Two PPHE components have been added to the course, which was originally developed by Associate Professor of Clinical Psychiatry, Peter J. Halperin, MD. The PPHE seminars are: Developmental Disabilities Across the Life Span: Assessment and Treatment, presented by John Pomeroy, MD, Director of the Cody Center for Autism; and The Law and Accessing Services for People with Developmental Disabilities, presented by Sue Lesco, Director of Family Support Services for the Cody Center and PPHE Coordinator.

The PPHE program at Stony Brook for both pediatric and family medicine residents is conducted by Susan Guralnick, MD (pediatric residency director and PPHE project director), Janet Fischel, PhD. and Dr. Pomeroy. Arnold Jaffe, PhD has been instrumental in working with the family medicine residents.

Transitioning from Pediatrics to Adult Care

The New York State Institute for Health Transition Training was created at the Center for Neurodevelopmental Pediatrics at SUNY Upstate Medical University in 2006 to promote self-determination, to optimize health and well-being, and to improve access to health care and the quality of health care that is delivered to young people with developmental disabilities aged 14-25 years in New York State.

The Institute has developed a curriculum and toolkit that youth with developmental disabilities can use to develop the skills needed to transition successfully from pediatric care to the adult health care system. The curriculum and tools are designed to recognize and promote collaboration among youths, service coordinators, families, and health care providers.

The interactive website, which will be launched July 2008, includes the following tools:

- Checklist to determine health transition readiness
- Goal setting tool to define roles and set priorities during the transition process
- Evidence-based health maintenance guidelines for adult healthcare
- Search engine for accessing transition-related services and service coordination in New York State
- Transition information form for summarizing medical history
- Interactive audio and text templates for rehearsing health care encounters

The curriculum is presented in a variety of ADA accessible formats, including video and audio and interactive web-based materials. The curriculum can be used for self-study or by groups with a moderator guide. Training sessions are available throughout New York State to introduce users to the curriculum and tools. The Institute provides 1-hour “academic detailing” sessions at primary care medical offices as well as ½ day workshops for groups of parents, service coordinators, youths, and interested others. An on-line version of the curriculum is available at www.HealthyTransitionsNY.org . Continuing education credits (CME CNE etc) will be provided to health care practitioners who complete the course.

Rx HEALTHY Transitions

Skills I can work on...

- ☐ Scheduling an appointment
- ☐ Getting health insurance
- ☐ Deciding about guardianship
- ☐ Speaking up at the doctor's office
- ☐ Understanding my disability
- ☐ Managing medications
- ☐ Keeping a health summary
- ☐ Looking into service coordination
- ☐ Setting health goals
- ☐ Finding community resources

www.HealthyTransitionsNY.org

Funded by the New York State Developmental Disabilities Planning Council, the Institute represents a collaboration among pediatricians and family practitioners at SUNY Upstate Medical University and the NYS Area Health Education Center System and practice-based research networks throughout New York State. The Syracuse University School of Information Studies, the Central New York Developmental Services Office, Parent to Parent of NYS, Self-Advocates of NYS and the Burton Blatt Institute at Syracuse University are also founding partners.

For more information on this project, please contact the Health Transition Training Institute: *Nienke Dosa*, MD*;* Project Director; *Jeffrey Tamburo*, LMSW, Project Administrator, NYS Institute for Health Transition Training, Department of Pediatrics, SUNY Upstate Medical University. 750 East Adams Street. Phone: 315-464-7504, tamburoj@upstate.edu

Family Medicine Residency Programs with PPHE grants meet

Six family medicine residency programs with DDPC grants to implement the Parent Partners in Health Education (PPHE) met in March to discuss their experiences. The group of graduate medical educators agreed that the family medicine focus on patient-center care and the importance of effective communications with families and children makes the specialty a critical link in working with special needs populations.

- Family medicine residents tell their PPHE project directors that they want to learn more about pediatrics and the care of children with special needs. Often, residencies do not provide sufficient clinical experience and didactic lectures to prepare residents to feel comfortable and confident in their knowledge and skills to provide primary care to children and adults with developmental disabilities.

- ACGME requirements for family medicine specify a wide range of experience, including four months of structured experience in the care of infants, children and adolescents. Training and experience with families and children with developmental disabilities is desirable but not required under current guidelines.

- Most family medicine residency programs lack faculty who are knowledgeable and experienced with working with children with developmental disabilities. This situation can be addressed through faculty development and/or active faculty participation in the PPHE curriculum.

- Family medicine practitioners tend to use parent evaluation screening tools (e.g. PEDS or Ages and Stages) rather than the Denver II for screening.

- Family medicine continuity clinics tend to have many more adult patients than pediatric patients. This may limit the residents' experience with children. Community agencies can assist by providing resident clinical experiences as well as an understanding of how various agencies and individual health care providers contribute to a child's well-being.

- Family medicine practitioners often accept adults with developmental disabilities who "age-out" of pediatrics.

Meeting participants included *Nienke Dosa, MD*,SUNY-Upstate, Syracuse; *Andreas Cohrssen*, MD, Institute for Urban Family Health, New York City; *Samuel Sandowski*, MD, South Nassau Communities Hospital, Oceanside; *Paola Carugno, MD* and *Paula Amendola*, MD , St. Barnabas Hospital, Bronx; *Nicole Cocomazzi*, St. Elizabeth Medical Center, Utica; *Arnold Jaffe*, PhD, Stony Brook University Hospital; *Karen Edwards*, MD, and *Sonia Valez*, MD, New York Medical College, Valhalla.

What's in a name?

Names and words have powerful meanings. The Self-Advocacy Association of New York State (SANYS) is leading a movement to drop the term "mental retardation" from common language and from the name of the state agency, the Office of Mental Retardation and Developmental Disabilities (OMRDD), a move supported by the OMRDD Commissioner Diana Jones Ritter. SANYS's February 2007 Legislative and Policy Platform explains that, "Hey, we've changed, but the name hasn't. It's time it did." Negative words like "idiot" and "moron" are fading out of use, and so should the derogatory phrase "mental retardation." SANYS executive director, *Stephen Holmes*, wants to hear ideas for new names for the state agency. One proposed name is the Office of All People with Developmental Disabilities. The discussion will continue at the next statewide October 30-November 1, 2008.

OMRDD offers a wealth of legal and programmatic information for providers, individuals, and families on its website, http://www.omr.state.ny.us/. Topics include guidelines on do not resuscitate, informed consent, health care choices, HIPAA requirements, overnight summer camps for adults with developmental disabilities, and a catalog of training and development program for providers of supports and services to individuals with developmental disabilities.

New interactive site for clinicians serving women with disabilities

The American College of Obstetricians and Gynecologists (ACOG) has placed an educational resource for clinicians serving women with disabilities on its website, http:// www. acog. org. This recorded slide program , ***Reproductive Health Care for Women with Disabilities*** assists women's health care clinicians with office skills to assist with their care of women with physical, developmental or sensory disabilities giving specific information for reproductive health care. Available now are the first two parts of a six part series, covering the scope of disability in women, sexuality and psychosocial issues, the GYN examination, and GYN health screening. A PowerPoint presentation with scripted notes is available for download.

Best Practices in PPHE

- *Bill Bryson-Brockman*, PhD, PPHE Project Director and Chief, Behavioral Pediatrics, Winthrop University Hospital, Mineola, sees personal relationships with community agencies and other professionals in the developmental disabilities field as a major benefit of PPHE. Knowing how to work as part of a team is critical for an effective primary care provider.

- *Nicole Cocomazzi*, PPHE coordinator for St. Elizabeth Medical Center, Family Medicine Residency Program, sees a big benefit of the program for foreign-trained physicians. In addition to expanding their knowledge of disabilities, their program includes role-playing to develop interviewing skills that may be applied to any professional encounter.