Parent Partners in Health Education Update

Issue #6 Winter 2010

This issue identifies resources to expand residency training on working with families and individuals who have developmental disabilities.

Contents

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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Core Competency Areas in Disability-Related Learning

Kristi L. Kirschner, MD and Raymond H. Curry, MD wrote an interesting article in the September 23, 2009 JAMA: "Educating Health Care Professionals to Care for Patients with Disabilities." They began with a quote from the US Surgeon General's *Call to Action to Improve the Health and Wellness of persons with Disabilities* that asserts that individuals with disabilities have worse health status than people without disabilities, largely due to inadequate resources. The report identifies the failure of medical education programs to teach concepts of disability as the primary cause of this inequity.

Kirschner and Curry lay out six core competency areas to guide the further development of disability-related learning objectives in health professions curricula. They suggest that medical students and residents acquire the following knowledge and skills:

1. A conceptual framework of disability in the context of human diversity, illness, the life span, and the constructed social and cultural environments;
2. Skills for assessing the level of disability, the functional consequence of illness, and the social and physical environments of patients with disabilities along with considerations for treatment and management;
3. General principles and etiquette for interacting with persons with disabilities;
4. Appropriate knowledge about interdisciplinary clinical care teams, the different roles and functions of various team members, and other disability-specific resources in both the health care system and the community;
5. The legal requirements of the Americans with Disabilities Act in health care and the concepts of universal design – not just for the built environment, but for all aspects of patient- centered care, including medical

equipment, staff procedures and training, and communication practices; and

6. Patient-centered care and the importance of understanding quality of life from patients' perspectives. (page 1134)

Kirschner and Curry discuss strategies for implementing more disability-related material in medical education and recommend that a robust process be pursued to refine, specify and standardize ways to include these competencies in both undergraduate and graduate medical education. These recommendations are consistent with the learning goals and content of Parent Partners in Health Education.

Kirschner KL; Curry RH. Education health care professionals to care for patients with disabilities. JAMA, 2009 302(9): 1334-1335.

The Surgeon General's Call to Action to Improve the Health and Wellness of persons with Disabilities. *http://www.surgeongeneral.gov/library/disabilities/*. Accessed March 16, 2010.

Introduction

While the Parent Partners in Health Education (PPHE) has multiple learning objectives, the overarching purpose is to help residents develop the skills, knowledge, and attitudes to work effectively with families and individuals (both children and adults) who have developmental disabilities. Through visits with volunteer families and with the community agencies that provide services to individuals with disabilities, residents become more comfortable and confident in their dealings with both the family and the individual with a disability.

Research has identified both family dissatisfaction with physician knowledge and physician recognition of gaps in their training to work with family and individuals with disabilities.

An important element in improving both family and physician satisfaction is an awareness of family expectations for their loved one's care. Sometimes it's a personal physician-parent-patient connection; other times, it's the knowledge of resources for either the physician or the parent. This newsletter identifies some basic resources that may be useful in graduate medical education. Resources are provided in twelve categories.

Assessment

Introduction to Developmental and Behavioral Screening by Frances P. Glascoe, Ph.D. and Henry L. Shapiro, MD.
Provides an introduction to screening young children for development and behavior problems in primary care, emphasizing standardized tool. Learning objectives: Impact of screening, knowledge of: specific screening instruments, screening versus referral, and under-referral in screening.
http://www.dbpeds.org/articles/detail.cfm?id=5

AAP Policy Statements on Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. Policy reaffirmed 2/1/10. This statement provides an algorithm as a strategy to support health care professionals in developing a pattern and practice for addressing developmental concerns in children from birth through 3 years of age. The authors recommend that developmental surveillance be incorporated at every well-child preventive care visit, that concerns be promptly addressed with standardized developmental screening tests, that screening tests should be administered regularly at the 9-, 18-, and 30-month visits. http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/405

First Signs is an organization dedicated to educating parents and professionals about autism and related disorders. The website offers resources for monitoring developments, concerns about a child, screening and referral process and sharing concern. Materials include articles, books and literature, web sites, videos and DVDs http://www.firstsigns.org/

See section following on Individuals with Disabilities Education Act (IDEA)

Assistive Technology

Assistive Technology Decision Making. Assistive Technology Training Online (ATTO) that uses a decision-making process that allows parents and teachers to identify specific assistive devices and classroom strategies that coordinate efforts to improve classroom learning.
http://atto.buffalo.edu/registered/DecisionMaking/

Communicating with children and families: from everyday interactions to skill in conveying distressing information. Levetown M and the Committee on Bioethics. Pediatrics: 121 (5): 1441-1460, 2008 Available at http://pediatrics.aappublications.org/cgi/content/full/121/5/e1441

Desch LW, Gaebler-Spira D, Council on Children with Disabilities: Prescribing assistive-technology systems: focus on children with impaired communication. 2008. Pediatrics 121(6): 1271-1280. http://aappolicy.aappublications.org/cgi/content/full/pediatrics;121/6/1271

New York State Office of Advocates for Persons with Disabilities. TRAID Project. TRAID's goal is to increase the access and acquisition of assistive technology in the four domain areas of education, employment, community living and information technology/telecommunications. Through the 12 Regional TRAID Centers (RTCs), staff provide information, training, device demonstration and loan, technical assistance and advocacy on how to obtain and use assistive technology services and devices. The TRAID Project in collaboration with the NYS Department of Health-Early Intervention Program provides partial funding to the RTCs for equipment loan libraries for infants and toddlers with disabilities and their families. The Project also operates and maintains the TRAID-IN Equipment Exchange program. www.cqcapd.state.ny.us/ Click on Assistive Technology/TRAID left side lower page.

Communication Skill Training

Buck R, Baile W, and Korsch B. Practical Guide to Communication Skills in Clinical Practice. 1998. A set of four CD ROMs or five DVDs constituting a comprehensive guide to communication skills, including how to break bad news, with over 40 filmed scenarios demonstrating practical ways in which communication techniques can improve patient care and support. Contents include:

Communication Skills- The Basics, Dealing with Feelings, Breaking Bad News, Special or Difficult Situations, Children and Their Parents, Uncovering the Hidden Problem, Palliative Care and End-of-Life Issues, Genetic Testing and Counseling. Details available at www.cinemedic.com/products/communication_skills.html

Adults with disabilities. Lezzoni LI: Going beyond disease to address disability. New England Journal of Medicine: 976 – 979, September 7, 2006.

Cultural Competence

American Academy of Pediatrics. Cultural Competence Resources and Tools, including HRS Cultural Competence Resources for Healthcare Providers, Community Toolbox-Cultural Competence Toolkit, and Healthy Care for healthy Kids Toolkit-Cultural Competence Tools. www.aap.org/commpeds/resources/cultural_competence.html. Accessed on 6/15/09

Rogers-Adkinson DL, Ochoa TA, and Delgado B. Developing Cross-Cultural Competence: Serving Families of Children with Significant Developmental Needs. Focus on Autism and Other Developmental Disabilities: 18: 4-8, 2003.

Starr HL. The Impact of Culture on ADHA. Contemporary Pediatrics 2007.

Individuals with Disabilities Education Act (IDEA)

Part B of the IDEA provides funds to state educational agencies (SEAs) and local educational agencies (LEAs) to help them ensure that children with disabilities, including children aged three through five, have access to a free appropriate public education to meet each child's unique needs and prepare him or her for further education, employment, and independent living. Part C of the IDEA provides funds to each state lead agency designated by the Governor to implement statewide systems of coordinated, comprehensive, multidisciplinary interagency programs and make early intervention services available to infants and toddlers with disabilities and their families. http://www.nichcy.org/Laws/IDEA/Pages/Default.aspx

New York State Early Intervention Program, Department of Health http://www.health.state.ny.us/community/infants_children/early_intervention/index.htm

IDEA and Section 504 of the Rehabilitation Act of 1973 www.ed.gov/about/offices/list/ocr/504faq.html)

See Special Education below

Medicaid

Information on New York State's Medicaid Program is available at www.health.state.ny.us/health_care/medicaid/

New York State Developmental Disabilities Planning Council (DDPC)

DDPC is a federally funded state agency working under the direction of the Governor. The DDPC is responsible for developing new ways to improve the delivery of services and supports to New Yorkers with developmental disabilities and their families. The Council focuses on community involvement, employment, recreation and housing issues faced by New Yorkers with developmental disabilities and their families. Contact information: NYS Developmental Disabilities Planning Council, 155 Washington Avenue, Second Floor, Albany, New York 12210. Toll-Free Phone (Also TTY/TDD): 1-800-395-3372; Local Phone: 518-486-7505 FAX: 518-402-3505

New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) The OMRDD website contains a list of services, location of regional Developmental Disabilities Services Offices (DDSOs), a Guide to Choosing a Residential Service Provider, provider associations/voluntary agencies, links to the Office of Alcoholism and Substance Abuse Services and the Office of Mental Health.
http://www.omr.state.ny.us

Patient Centered Care

Institute for Family-Centered Care. Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System. April 2008.
www.familycenteredcare.org/pdf/PartneringwithPatientsandFamilies.pdf

Special Education

Special Education in Plain Language : A User Friendly Handbook on Special Education Law, Policies and Practices in New York was created by the Special Education Task Force to help families and educators gain the knowledge that they need to be able to effectively support students with disabilities during their school years. It includes information on the laws, regulations and policies affecting special education programs and services. Available from the New York State Developmental Disabilities Planning Council. Access at http://www.ebulletin.us/archive/2009/march/03_09_special_ed_guide.php

Transitioning from Pediatric to Adult Health Care

New York State Institute for Health Transition Training website www.HealthyTransitionsNY.org created by SUNY-Upstate's Center for Development, Behavior, and Genetics with funding from the New York State Developmental Disabilities Planning Council. The Institute developed and maintains a curriculum and tools for use by youth with developmental disabilities (ages 14-25), families, support networks and health care providers.

Adolescent Health Transition Project. A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities. Included information for teens and young adults, parents and families, health care providers and educators, and specific information on diabetes and adult health care guidelines. Sponsored by the Children with Special Health Care Needs Program, Washington State Department of Health.
http://depts.washington.edu/healthtr/

Assistive Technology Companion Guide to the Transition Health Care Check List: Healthcare Skills Needed for Independence. Developed by the Pennsylvania Initiative on Assistive Technology, this guide identifies ways that AT can help transitioning students perform tasks that have been identified as health care skills needed for independence. Available at http://disabilities.temple.edu/programs/assistive/transitionListGd.shtml accessed on 06/09/09.

A Work Book for Young Adults, Their Families, and Their Medical Care Providers. Laura Pickler, MD. 2005. This work was supported by a grant from Champions for Progress # 2580410 and AAP/CATCH # 2580398. Available at http://www.cdphe.state.co.us/ps/hcp/transition/workbook.pdf accessed 06/09/09.

Since you're not a kid anymore, it's time to be more in charge of your health care. A transitional guide for teens in middle school, this site is colorful, contains cartoons, and helps teens look at themselves in positive ways. Available at http://hctransitions.ichp.ufl.edu/pdfs/

My Health, My Choice, My Responsibility. This is a training program developed at Westchester Institute for Human Development in collaboration with the Self-Advocacy Association of New York State (SANYS). Its purpose is to help individuals with developmental disabilities make healthy choices in daily life and speak up for good health. .
http://www.wihd.org/matpub/matpub_index.html

Vocational and Educational Services for Individuals with Disabilities (VESID)

VESID is a state agency that helps eligible individuals with disabilities become independent through education, training and employment. VESID provides vocational rehabilitation services to eligible individuals to prepare them for suitable jobs. These jobs might be in the competitive work force, in self-owned businesses, in supported employment on employer sites, or in sheltered workshops. VESID can also help with independent living arrangements by referrals to local Independent Living Centers.
http://www.vesid.nysed.gov/