



Parent Partners in Health Education Update

Issue #5 Fall 2009

This issue is devoted to starting a PPHE program.

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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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Is voluntarily adding new elements to a residency program possible?

When something is said by a recognizable person, the quote takes on added meaning, even if it is a version of an old proverb. For example, Lucille Ball said, "If you want something done, ask a busy person to do it. The more things you do, the more you can do."

A more recent version is: If you want something done, ask a busy person. They know how to manage their time.

So, the question for busy residency program directors is: why NOT add something like PPHE that is needed and valuable to the residency curriculum?

Too busy? That is definitely true but somehow eleven teaching hospitals, with sixteen residency programs, have managed to do just that. They incorporated PPHE into their existing residency programs.

Was it easy? Not particularly. It's like making any change. You assess how your residency program is meeting the needs for this training, plan, garner support, and proceed with an eye for refining both the process and the content.

Can PPHE be implemented perfectly the first year it is introduced? Probably not. There will inevitably be some tweaks to the process and the curriculum.

Will the residents gush with joy at new requirements? Maybe not the first year, but they will definitely accept the PPHE objectives and requirements as these were integrated into other residency components.

Is it worth it? Yes!

Getting your PPHE program started

The flexibility of the PPHE curriculum allows residency programs to choose the best way to integrate its elements into an existing residency program. The original curriculum was designed for primary care residencies (specifically pediatrics and family medicine) but can easily be adapted to other programs. More information on PPHE in specialty residency programs is provided the next section.

The PPHE components include the following:

- Four didactic lectures: Orientation to PPHE, Assessing Developmental Disabilities in Primary Care, Legal Aspects and Accessing Services for Children with Disabilities, and Doctor-Patient-Family Communications.
- Community Medicine Case Presentations

- Parent Partner Interviews
- Community Agency Interviews
- Clinical Experience with Children who have Developmental Disabilities
- Small Group Discussion Sessions
- Personal Reflections
- Program Evaluation

After becoming familiar with the PPHE curriculum goals, the first step is to evaluate your existing residency program in each of these areas, both by describing the training activities and evaluating their effectiveness.

- Do you currently assess resident competence for: assessing developmental disabilities, delivering family-centered care, communication skills appropriate for families with children who have disabilities?
- Do your residents become familiar with community agencies and the services they supply?
- Do your residents' complaints about patient "non-compliance" reflect a lack of appreciation for the day-to-day difficulties parent face?
- Do any of the community medicine case presentations address developmental disabilities?
- Do you think your residents get experience with families and children with developmental disabilities during their rotations and continuity clinic time?

If you are satisfied with what you are already doing, you can focus on those PPHE elements that would strengthen your residency program.

As part of you planning, consider:

- Where to conduct most of the PPHE activities (e.g. behavioral and developmental rotation, community medicine rotation, continuity clinic)
- Physician and non-physician faculty who are knowledgeable about families and children with developmental disabilities and who can support PPHE
- Internal leadership and support for the training
- Available staff to coordinate and administer the curriculum (e.g. recruiting parent partners and arranging for home visits, establishing relationships with community agencies)
- Clinical contact with children with disabilities at various stages of diagnosis and treatment, either at your teaching hospital or a community agency like United Cerebral Palsy, ARCs, or Easter Seals that provides medical services

Small group discussion sessions and personal reflections are valuable pedagogic techniques. If you are already using them, it would be easy to incorporate discussions and reflections about PPHE experiences. If you are not currently using one or both learning tools, consider different ways to incorporate them into your residency program. For example, the DDPC funded grantees found these components easier to include if the PPHE program were largely implemented in a designated rotation. Some chose to debrief residents about their experiences immediately after, say, a home visit and then have a group discussion at the end of the rotation. The reflections can be done impromptu or in response to structured questions, e.g. what did you learn that might apply to your clinical practice?

After clarifying priority goals and identifying potential resources, the next step is to define internal roles and responsibilities and garner support for the curriculum change. Key people in this step are the hospital administration, the Department chair, the Residency Program Director and coordinator, the Residency Education Committee, rotation faculty and preceptors.

Tips for getting ready

Eight of the PPHE grantees who have completed their three year projects offer some tips on getting started.

Winthrop Pediatric Residency Program, Mineola: Having six months to plan the details implementing the PPHE program was very helpful in setting up the necessary systems, including a coordinator, equipment, space, a free online web log to record resident experiences.

St. Elizabeth Family Medicine Program, Utica: A PowerPoint presentation was developed, as were orientation binders that included samples of case summaries, parent interview questions, community agency contact information, lecture forms, and resource material. Throughout the three years, residents were always given the opportunity to express their opinions and recommend changes in the program.

Stony Brook Pediatric and Family Medicine Residency Programs, Stony Brook: The Pediatric Residency Director (and the PPHE project director) enlisted the assistance of faculty members from both departments and partnered with the Cody Center of

Autism and Developmental Disabilities to present didactic lectures, observe clinical and home visits and distribute outreach materials. They prepared a manual and CD that included the history, mission, and goals of the project, schedules, timelines and required evaluation materials. The two residency programs arranged for meeting and conference days to take place at the same time to facilitate implementation of the PPHE program.

St. Barnabas Pediatric and Family Medicine Residency Programs, Bronx: The PPHE project directors met with the chairmen and residency program directors of each department and presented the PPHE curriculum to faculty at departmental meetings. At the time, the department of pediatrics had been educating their residents about individuals with developmental disabilities, but residents were not being exposed to the families, homes, or communities of these individuals. The family medicine residents were not receiving any formal training in developmental disabilities. PPHE became a new curriculum for family medicine, to be coordinated by the developmental pediatricians.

Maimonides Pediatric Residency Program, Brooklyn: Planning for the project was done by a core group that included a medical educator, psychologist, developmental pediatrician, and primary care pediatrician, who would develop and implement the curriculum. This group reported to and got input from the Residency Training Director and the Department Education Committee, as well as the Department Chair. The group adapted the original PPHE curriculum to make it relevant for an urban, multicultural setting with culture-specific needs and sensitivities. Incoming residents were open to the program, seeing this as an expected part of their residency program and an opportunity to learn from and connect with parents.

Morgan Stanley Children's Hospital at New York Presbyterian Hospital Pediatric Residency Program, Manhattan: An early decision to interview PPHE with other programs allowed the program director to greatly enhance the experience of residents with home visits and developmental disabilities. Already in place were home visits funded by a nonprofit foundation and a limited Project DOCC (Delivery of Chronic Care) program, in which parents of children with disabilities provided training and home visits for residents. The PPHE project expanded these efforts. The project was also able to incorporate an existing workshop on cultural competence as part of the PPHE training on Doctor-Patient-Family Communications.

New York Medical College Pediatric Residency Program, Valhalla: The PPHE program had the strong support of the medical school, the residency program, and the GME office of the medical school. Information sessions were presented to department chairs and members of the Graduate Medical Education Committee of the medical school. An article about PPHE was published in the on-line and print versions of the monthly medical school newspaper. A resident was a member of the planning committee. Presentations by program leaders and past PPHE trainees were made to first and second year residents to insure a uniform message and give the opportunity for questions and answers.

SUNY Upstate, Syracuse: The planning phase included development of community as well as resident advisory boards for the PPHE project. SUNY Upstate's administration was supportive from the outset and provided assistance with publicity and promotion of the PPHE program both within Upstate and in the community at large. The project directors presented the original curriculum to the department and hospital administrators, explaining that they would be customizing the curriculum. Having a defined curriculum made it easy to get support for the project.

PPHE in adult care residency programs

The basic premise of PPHE is that physicians are more comfortable and confident in working with people who have developmental disabilities (and their families) when the physicians have had training and experience with this population. This translates to improved physician, parent, and patient satisfaction with the quality of care provided. There are numerous research findings, refereed journal articles and commentaries that support the dissatisfaction all parties have with the current situation. Also important is the fact that individuals with developmental disabilities are living longer and graduating from pediatric care to adult medical providers, e.g. internal medicine, family medicine, and other specialties. The New York PPHE projects included pediatric and family medicine residency programs. One of the family medicine residency programs focused on experience with adults who had a developmental disability. The PPHE curriculum was expanded to address both adults and children.

The flexibility of the PPHE curriculum allows other medical residency programs to adopt, modify or add the elements that fit their needs.

- If the lecture topics don't seem to apply, identify what you see as appropriate topics. For example, if you don't assess for developmental disabilities, consider focusing on clinical practice guidelines specific to the medical conditions most often seen in your specialty's practice, generally as health issues for adults with developmental disability, or specifically on, say, aging issues of adults with developmental disabilities.
- While many community agencies serve both children and adult, e.g. United Cerebral Palsy and ARCs, others focus on specific services like transportation, housing, vocational or rehabilitation services. A basic understanding of community agencies will benefit all patients.
- Parent partners, as members of the residency teaching team, give insights into the day-to-day lives of individuals who have developmental disabilities. This information is valuable whether it is given during a home visit or through some other venue. Once you identify what your residents need to know in order to provide effective medical care, you can decide how to structure the visits with parents or caregivers to solicit information appropriate to clinical practice.

CDC feature on people with disabilities

The website for the Centers for Disease Control and Prevention features information and resources on health and longevity for people who have disabilities. In addition to tips for individuals with disabilities, it offers tips for Improving the health and wellness of people with disabilities. The tip list includes:

- See the whole person, not just the disability.
- Speak directly with the person with a disability, rather than through a third party.
- Speak with adults as adults, and children as children.
- Ask the person with a disability if he or she needs any help. Do not assume help is needed.
- Be aware and patient of the extra time it might take a person with a disability to speak or act.
- Understand that not having access to work, school, health care, or fun things to do can cause more problems than a disability itself.
- Be the person who makes a difference.

- Respect what a person with a disability can do. See the ability in disability.

Check out the website at:

<http://www.cdc.gov/Features/Disabilities/#improving>

Training for dentists to aid people with developmental disabilities

Individuals with developmental disabilities suffer more dental disease than non-disabled individuals and have greater difficulty locating dental care than other underserved groups, according to the NYS Task Force on Special Dentistry (NYSDJ, June/July 2009, page 24). With funding from the NYS Developmental Disabilities Planning Council, the State Office of Mental retardation and Developmental Disabilities (OMRDD) and the task force developed a series of educational modules, which offer three hours of continuing education credit, designed to teach dental professionals about topics related to the dental treatment of persons with disabilities.

Local dental societies are encouraged to increase access to care for the disabled population through special committees or task forces. The Ninth District Dental Association is providing a model of action by identifying community partners, forming emergency teams of providers and educating the members using a continuing education model, "A Primer on Treating Individuals with Developmental Disabilities."

Residency programs can work with their local dental groups to encourage projects to inform and educate dentists on the needs of individuals with developmental disabilities. When individuals with disabilities are seen in clinics, residents could check on oral health needs.

PPHE website

The New York State Council on Graduate Medical Education has added PPHE materials to its website, www.nyhealth.gov/professionals/doctors/graduate_medical_education. Click on Parent Partners in Health Education (left column) for an overview of the program, previous PPHE Newsletters, and the Final Report for the 2005-2008 PPHE Projects. The recent Final Report for the 2006-2009 PPHE Projects will be posted soon.
