Parent Partners in Health Education Update

Issue #7 Summer 2010

Special Issue on PPHE Best Practices

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 was provided by the NYS Developmental Disabilities Planning Council (DDPC). The NYS Council on Graduate Medical Education (COGME) provided technical assistance to PPHE grantees and conducted 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.)

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It sounds unbelievable, but given the number of teaching hospitals, the number of residency programs, and the number of years PPHE was in use at the various sites, there is a total of 43 years experience with this curriculum in New York! In addition to providing a rewarding experience for the residents, a great deal was learned about how to make PPHE a dynamic element of a residency program.

This last issue of the Parent Partners in Health Education Update focuses on the best practices recommended by PPHE grantees to successfully introduce, integrate, and sustain PPHE in a residency program.

Overall, three years experience with the PPHE program has convinced me that the curriculum is very well designed, with components that support each other and that are sustainable given the large numbers of families with developmentally disabled children. Local physicians have contacted us since the beginning of the program to recommend families for inclusion in PPHE. The response from parents has been amazing. When parents become aware of the program, most are interested in helping residents learn about the care and attention they and their children need. One parent summed it up: "The resident was mystified by our answers (to interview questions) and this shows that this program is necessary." The parent-partner interview seems to be the most powerful experience in the program.

Bill Bryson-Brockman, PhD, Winthrop University Hospital

Background. In 2005, the New York State Developmental Disabilities Planning Council began a five-year initiative to fund pilot projects using Parent Partners in Health Education (PPHE). PPHE is a curriculum that expands medical resident experiences in working with families and individuals with developmental disabilities. Grants were competitively awarded to four teaching hospitals in each of three cycles, for a total of 12 grantees. Because some of the hospitals included more than one residency program, sixteen residency programs were involved: eight in pediatrics, seven in family medicine, and one in psychiatry. All of the grants have ended. A list of the grantees with contact information is provided at the end of this newsletter.

The PPHE Curriculum offers didactic and experiential learning to complement elements in existing resident program curricula. Each project used the *Parent Partners in Health Education* curriculum, which consists of the following components:

- Parent Interviews that help the resident gain an understanding of the experiences of raising a child with a disability from the perspective of the family.

- Four Didactic Lectures that provide specific, detailed content including an orientation session, Assessment of Developmental Disabilities in Primary Care – Denver II, Legal Aspects and Accessing Services for Children with Disabilities, and Doctor-Patient-Family Communication.

- Community Agency Interviews that allow the medical residents to learn directly about available community resources and including at least one interview with an agency providing services to the paired family.

- Clinical Experiences that provide direct experience with children/adult with developmental disabilities, give the resident the opportunity to develop essential skills, and highlight the integration of clinical, family and community aspects of care.

- Community Medicine Case Presentations through which residents share medical, social, and educational details about their assigned family and child with other residents and faculty.

- Small Group Discussions that provide a forum for residents to participate in informal peer-to-peer exchanges.

- Personal Reflection Logs that allow residents to record notes, feelings, and experiences about their contacts with children, parents, and providers.

Models. Although using the same curriculum, residency programs implemented the curriculum differently. Some of the different models were:

One-year programs offered in the year that pediatric residents have their behavioral and developmental rotation or that an appropriate family medicine rotation was chosen.

Multi-year programs for either PGY-2s and PGY3s, or for all three residency years.

Concentrated programs conducted during 3-4 week sessions.

BEST PRACTICES

Introducing PPHE

Careful attention to how PPHE – or any program - is introduced makes a difference on how the administration and faculty accept it. Each grantee introduced PPHE with forethought to include key people. Information should be given in faculty meetings, one-to-one discussions, newsletters, memos, or any other forum that reaches key hospital personnel. Include the hospital's Chief Operating Officer, administration, department chairs, other residency programs directors, preceptors, attending physicians, and chief residents.

Issue a press release about the project to the general community, OMRDD offices, family support coordinators, service and educational agencies and the medical community that work with individuals who have developmental disabilities.

Program Leaders

Select PPHE leaders who have a personal commitment to the goals of the program. The project director is a key figure in adapting the PPHE curriculum to the residency program, motivating program leaders, and ensuring that the curriculum goals are achieved. A dedicated project director develops and fosters ongoing personal relationships with community agencies and other professionals in the developmental disability field that can make PPHE both successful and sustainable.

Create an oversight team of faculty, including the education committee, to problem-solve and champion the program.

Designate a person (e.g., social worker, residency program coordinator, or office administrator) with dedicated time to coordinate PPHE activities. This person should be aware of the residents' schedules

and have the authority to schedule PPHE assignments, e.g., the home and community agency visits.

Many of the PPHE grantees recommend that a home visit guide accompany residents to model appropriate interview behavior, prompt questions that the resident may miss, and debrief the resident after the home visit. The guide should be someone familiar with home visits and could be another faculty member, a social workers, a nurse, a psychologist, or any professional with skills and experience to assist the resident.

Resident Buy-In

Residents are often leery of adding new expectations to their residency programs until they personally experience the benefits of the changes. Involving residents in planning, problem-solving, and tweaking the PPHE curriculum increases their stake in making it successful.

All of the PPHE grantees stressed the importance of listening to the concerns of all program participants. Systematic collection of feedback from residents and families immediately after the visits allows for speedy "course corrections" and for longer term aggregation of feedback to inform systematic program changes.

Part of insuring resident buy-in is to provide sufficient information about PPHE objectives and expectations. One effective way to accomplish total resident participation is to clearly identify each participant's responsibility, schedule home visit interviews during the residents' working hours and schedule regular times for the residents to update and review progress, answer questions and make changes.

Another good idea is to invite residents who just completed PPHE to speak with residents starting the program. The first group describes their experiences with families and community agencies and gives insight into the benefits of PPHE.

For residency programs offering PPHE to PGY2s, meet with all PGY1s as a group just before the transition into PGY2 year, in order to describe the PPHE experience and set out expectations and answer questions.

Important Staff

The presence of a developmental pediatrician can facilitate implementation of PPHE in a variety of ways. Developmental pediatricians can provide lectures, lead small group discussions, and conduct one-to-one training during designated time for PPHE training. In family medical residencies, developmental pediatricians can add teaching and experiences not available from other family medicine faculty. PhD psychologists were also a great resource on psycho-social issues.

When the decision is made to augment faculty with outside staff, the residency program may partner with nonprofit community agencies that can provide access to patients, clinical experiences, and educators. One PPHE grantee partnered with United Cerebral Palsy of South Nassau; another worked with AHRCNYC.

At several sites, PPHE staff realized that the residents were learning skills and gaining knowledge that key faculty and/or attendings did not have. Two of the grantees organized faculty development programs to share PPHE material with attendings. One family medicine residency program included faculty participation in their PPHE program. The faculty was willing to attend didactic sessions throughout the grant and partner with families for one year. Faculty member became familiar with lecture content and the lessons of home and community agency visits, and were prepared to continue PPHE after funding ended.

Three Year Approach

While choice of a PPHE model (i.e. complete the PPHE curriculum in a single year or spread out over two or three years) should based on it fit with the residency program, many PPHE grantees endorse offering PPHE activities during each residency year.

Justifications for offering PPHE over three years include: (1) more general exposure to developmental disabilities; (2) repetition to aid learning; (3) the differing perspectives of different levels of training to highlight different aspects of care of individuals with developmental disabilities; (4) recognition of the importance of PPHE's lessons; and (5) more integration into the residents' overall approach to delivering health care. When individual children can

be seen over time, the resident can witness the changes that occur over time for the child with a disability and their family.

Integrating PPHE into the ResidencyCurriculum

Developing a flexible curriculum that fits into the existing residency program (rather than making it an add-on) makes it easier to fit the PPHE components into the resident's busy schedule. Two examples:

(1) PPHE home visits can be added to an existing Community Pediatric home visit program, giving residents insights on the impact of disability on transportation, scheduling appointments, juggling the needs of other family members, and coordinating care, among many other concerns.

(2) Blending PPHE activities with other elements of the residency program e.g. training on cultural competence or on communication skills, can satisfy two requirements in a single event.

Managing Schedules

The scheduling of home and community agency visits was probably the most challenging aspect of implementing PPHE. And as one would expect, the greater the number of residents involved, the more difficult the scheduling. Residents are incredibly busy and while they may be motivated to learn from the PPHE experience, they benefit from administrative help in scheduling.

- Use a designated rotation to complete most of the PPHE activities. The behavioral-developmental rotation was most commonly used. Other options were community medicine and the continuity clinic.

- Choose a specific rotation during which the PPHE coordinator has the ability to schedule activities.

- Do not leave assignments open-ended or expect the residents to arrange agency and home visits.

- Schedule the residents' activities in advance into the designated rotation. This can be done by the residency program coordinator or in collaboration with the rotation director. It is important to have clearly identified people responsible for helping residents complete the program.

- Schedule a specific meeting time, e.g., on the first Friday of each month, to allow time for PPHE activities.

- With a large number of residents, split resident home visit between the fall and spring.

Didactic Lectures

Most project directors felt that the repetition of lectures is important. Residents have to learn so much information that the repetition seems to be helpful. The annual repetition of didactic lectures assured that each resident class was exposed to the material.

Several approaches were used to encourage lecture attendance, such as designating specific days/times at a specific location for all PPHE lectures and including PPHE lectures in Grand Rounds, noon lecture series, and clinic lectures.

When PPHE activities were completed primarily during a designated rotation, lecture material was often covered in small groups with the residents taking that rotation.

Also, lectures were recorded on hospital-based IT systems and videotaped. Lecture materials and handouts were made available.

Aids to Learning

Look for ways for residents to learn something new at each family encounter. For example, ask residents to complete a short assessment of the child's adaptive behavior using the SIB-R (Scales of Independent Behavior-Revised) during the home visit. This gives the resident experience with the SIB-R and added some variety to the home visit. Choose a screening tool or other activity that fits your residency program requirements.

Videotape each resident doing a patient interview. Review the videotape with the resident and agree on one interviewing skill to improve**.**

Role- playing is an enjoyable way to practice and improve skills, e.g., giving unexpected/bad news. The

majority of residents are not familiar with home visits, so this practice helps. Role-playing is particularly helpful for foreign-trained residents who are new to the U.S.

Use narrative medicine as an approach to enrich small group discussions about PPHE experiences. The process is to ask the resident presenting his/her experience to take about five minutes to write what the mother would have said about her family and the impact of having a child with a disability. During this time, the other residents write questions they would like to ask the parent. Then the resident reads the mother's statement and responds to the questions in the mother's voice.

Because screening is a PPHE priority, reinforce the importance of screening by giving participants a Denver II kit.

Distribute First Person Language handouts to all residents and faculty and schedule a session on Cultural Diversity and Developmental Disabilities.

Recruiting Parents

Parents, as well as the residents, reported benefits from PPHE. Many parents said they felt their insights were validated by the residents listening to them and seeming to find that what was said was important and useful. Best Practices included:

(1) Develop a Parents' Manual on PPHE in English and other languages, e.g., Spanish, that are common in the community served by the hospital. This resource helps parents understand their role as teachers in achieving PPHE goals.

(2) Orient parents to PPHE shortly before a home visit is scheduled. It is easy to lose contact with parents when there was a long lag time between when the parents were recruited and trained, and when the residents were ready to make the home visit.

(3) Involve parents whose children are seen in the continuity clinic. The interactions strengthen the resident-parent-child connection, provide clear evidence that parents are willing and able to be teaching partners, and reinforce the resident's perception of the value of a medical home.

(4) Try to match the language of the resident and the parent partner. This makes it much more comfortable for the parents to express themselves and for the resident to learn.

Home Visits

Since home visits are a new experience for most residents, it is helpful to have those who had done their home visits speak about it to other residents. Invite residents with home visit experience to talk about their positive encounters to reassure other residents who may be concerned about safety and whether they will be accepted in the home.

Videotape residents who participated in PPHE as a way to introduce the PPHE curriculum to those in following years.

Residents, especially for the first home visit, may benefit from the presence of an experienced professional who models appropriate behavior. This preceptor can help focus on key issues that might otherwise be overlooked during the visit.

Provide residents with a list of sample interview questions for the home visit (as well as an outline for information to be gleaned from the agency visit). A home visit "etiquette tip sheet" is also useful. These steps also help residents be more comfortable venturing out from the medical center.

Debriefing

Writing reflections about what the resident has seen, felt, and learned is a useful way to process the experience. However, this exercise takes time, something that is in short supply for residents. Most PPHE sites replaced reflections with one-to-one debriefings.

Debriefing soon after the visit allows the residents to process and consolidate their experience. Debriefing residents one-to-one shortly after the home visit, rather than waiting a longer period of time to have enough residents for a small group discussion, proved more effective, since there is better recall for recent experiences. It also avoids the problem of gathering residents from different rotations and different locations.

Interdisciplinary Training

Interdisciplinary training, with joint home visits and small group discussions for psychiatry residents and pediatric interns, has benefits for both groups. The senior psychiatry residents are able to model interview skills for pediatric interns, and are excellent facilitators as well as participants in the small group discussions. The interdisciplinary model is particularly relevant to training of professionals who care for children and adolescents with dual diagnoses. Consider pairing primary care residents with other specialties.

Community Agencies

Part of the benefit of visiting community agencies is to learn how other health care professional contribute to the care of individuals who have a developmental disability. One PPHE site required that the home visit including seeing an Early Intervention therapy session, e.g. physical therapy, speech therapy, etc. This requirement complicated setting up the home visit, but it proved to be a valuable learning experience.

As with home visits, it is necessary to keep in touch with agencies that have agreed to resident visits. Be sure to remind the agency contact a few days before the planned visit to be sure that no problems have arisen to interfere with the visit.

Learn One, Teach One

Empower your residents and faculty to share what they have learned through PPHE. One PPHE grantee held a one-day symposium for other residency programs in the area. The host residents felt like they were the leaders and now the educators of others (even if it was outside speakers presenting). The event was so successful that it was offered again the following year. This effort increased the standing of the residency department, as the hospital administration felt proud of its role as educators and advocates.

Raising the Bar

PPHE efforts at one site inspired the dean of the medical school to convene a meeting to discuss the education of medical students, primary care residents, and hospital staff regarding developmental disabilities. Faculty leaders were assigned responsibility for specific areas with the goal of making services more adaptable, individually focused, and accessible to the developmental disabilities community.

While this is probably a given within the context of this program, the single most important component has been to assure that the residents have the opportunity to interview a family of a child with a disability regarding 1) the process of determining and learning about the diagnosis; 2) arranging treatment and service; 3) the attitude of medical and educational care providers toward the patient and the families; and 4) the impact that having a disability has on the child, the parent and the whole family. This process of getting to know a specific child and family highlights the important issues and makes them both personal and real for the residents. It increases their empathy and sensitivity as well as giving a story that helps the resident remember the issues better and prioritize them more realistically.
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Thank You, DDPC

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More Information on PPHE

COGME has placed information about PPHE, reports on Phases I, II, and III of the initiative, and the PPHE Updates on its website at http://www.nyhealth.gov/professionals/doctors/graduate_medical_education/

Parent Partners in Health Education Grants

PPHE Phase I Residency Programs 2005-2008

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