PARENT PARTNERS IN HEALTH EDUCATION

A curriculum to train medical residents to work with families and children with developmental disabilities

FINAL REPORT FOR 2005 - 2008 PROJECTS

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This report summarizes a three-year demonstration project of the Parent Partners in Health Education (PPHE) curriculum, funded by the Developmental Disabilities Planning Council (DDPC) between 2005 and 2008. Three teaching hospitals and one academic medical center, listed below, implemented the PPHE curriculum in seven medical residency programs during the first phase of this initiative. The New York State Council on Graduate Medical Education (COGME), with the New York Department of Health, was awarded a DDPC grant to provide technical assistance and overall evaluation of the demonstrations.

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Acknowledgement

The effort to increase physician training on working with families and children with developmental disabilities has been a major initiative by the Developmental Disabilities Planning Council (DDPC) under the leadership of Executive Director Sheila Carey. DDPC's Children's Issues Committee, staffed by Robin Worobey, DDPC Program Planner, and Kerry Wiley, DDPC Program Research Specialist, did careful research on the topic, identified Parent Partners in Health Education (PPHE) as a viable curriculum, and designed a five-year strategy to implement and evaluate this curriculum for primary care residency programs in New York. Their efforts were enthusiastically received by graduate medical programs who also wanted to better prepare pediatricians and family medicine physicians to work with families and children with developmental disabilities. The amount of training and experience required of medical residents is extensive. Yet, the PPHE curriculum is seen as enriching the residents' experience. The results of Phase I of DDPC's initiative are heartening, and there are two more phases of demonstrations that will be completed over the next two years. This effort places New York State in the forefront of actively improving graduate medical education on developmental disabilities.

Copies of this report may be obtained from:

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The report is also available on the website: http://www. nyhealth.gov/nysdoh/gme/main/htm

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Structure of this Report

The Overview and Evaluation chapters include comparative information on the PPHE curriculum as applied by the four grantees in Phase I. The chapters on individual grant sites describe unique aspects of each program. Each grantee describes their approach to implementing PPHE, preparations to start the program, challenges faced and resolved, relationships with community agencies, the process for recruiting parents, designing clinical experiences, lessons learned, best practices, and their efforts at sustainability. The last chapter presents evaluation data on the four demonstration projects.

OVERVIEW

Background

In 2005, the New York State Developmental Disabilities Planning Council (DDPC) began a multi-year initiative to demonstrate the effectiveness of a curriculum to expose primary care medical residents to individuals with developmental disabilities and the caregivers of these individuals. The Parent Partners in Health Education (PPHE) curriculum was first developed by the University of Illinois College of Medicine and funded by the Illinois Council on Developmental Disabilities. In Phase I of the New York demonstrations, three-year grants were awarded to four institutions with seven primary care residency programs to implement, evaluate, and integrate the curriculum as part of their physician training to work with families and children with developmental disabilities. The selected residency programs had submitted applications to the DDPC and were awarded the grant via a competitive process. The selected programs spent the first six months of the 42 month grant cycle on program planning and development and the remaining 36 months on implementation. The New York State Council on Graduate Medical Education (COGME) was awarded a grant to provide technical assistance to the grantees and to conduct the overall program evaluation. Two additional demonstration phases, consisting of four institutions in each phase, were subsequently awarded three year grants, with one phase beginning in 2006 and the other in 2007.

This is the final report of the Phase I PPHE grants implemented between 2005 and 2008 by St. Barnabas Hospital Pediatric and Family Medicine Residency Programs, Bronx, NY; St. Elizabeth's Medical Center Family Medicine Residency Program, Utica, NY; Stony Brook University Hospital, Pediatric, Internal Medicine/Pediatric, and Family Medicine Residency Programs, Stony Brook, NY; and Winthrop Hospital, Pediatric Residency Program, Mineola, NY.

Project Objectives

The objectives of PPHE are to:

- Improve medical residents' awareness of the day-to-day issues faced by families caring for children with disabilities;
- Improve medical residents' knowledge of non-medical supports and potential sources of referrals within the community;
- Increase collaboration and communication between medical residents, non-medical human service professionals and families of children with disabilities;
- Enhance medical residents' skills on developmental disabilities as part of an overall patient-centered approach to the care of children with disabilities and their families; and
- Enhance satisfaction with primary care services for children with developmental disabilities and their families.

PPHE Curriculum

The PPHE curriculum includes the following eight required 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 - an organizational session, Assessment of Developmental Disabilities in Primary Care (using the Denver II assessment tool), 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 include at least one interview with an agency providing services to the paired family.
- Clinical Experiences that provide direct patient care experience with children and adults with developmental disabilities and give the resident opportunities to develop essential skills and highlight the integration of clinical, family, and community aspects of care.
- Community Medicine Case Presentations that allow residents to share their knowledge of medical, social, and educational details about their assigned family and child with other residents and faculty.
- Small Group Discussions that create a forum where residents can share in informal peer-to-peer exchanges.
- Personal Reflection Logs that contain a record of residents' notes, feelings, and experiences about their contacts with individuals with developmental disabilities, their parents, and providers.
- Evaluation and Research that measures the success of the PPHE curriculum at increasing resident knowledge and skills and improving attitudes on disability issues.

Unique PPHE Features

The PPHE curriculum is unique in that its focus is specifically on individuals with developmental disabilities. The curriculum was originally designed to focus on children, but the Phase I 2005-2008 experience has shown that the curriculum could easily be adapted for adults. The two truly unique elements of this program are the home and community agency visits.

As the phrase implies, parent partners (i.e. parent volunteers who share their lives and experiences with the residents) become an informal part of the residency teaching team. Residents, as well as faculty physicians, usually see children for routine office visits or during crises, and have no knowledge about the family's and child's daily life. Seeing the home environment, meeting others in the household, learning about and observing the care and professional services received by the child, and appreciating the stresses faced daily by the family make a difference. This knowledge adds to the physician's ability to provide patient-centered care. Parents were recruited to participate in PPHE through their involvement in hospital continuity clinics, contact from the PPHE project directors, and referrals from community agencies. One family medicine residency program decided to partner with the New York State Office on Mental Retardation and Developmental Disabilities (OMRDD) to have their residents paired with residents at local group homes instead of being paired with parents and children.

The philosophy inherent in the PPHE curriculum is that the physician should be a primary support and resource for the family. Hence, the physician should be knowledgeable about the community agencies that serve families and children with developmental disabilities. Residents participating in PPHE visit community agencies with their paired child and family to observe their experiences in other areas of health care. This is a good opportunity to gain an appreciation of how team work benefits the individual with developmental disabilities. Often, the agency visits involve observations at schools where the residents see the child in an integrated or a special needs educational setting.

Grantee Activities

Each grantee determined the best model for implementing PPHE into the current residency curriculum. Some chose to implement the curriculum in one year only. Others chose to use the curriculum during two or three years of the residency program. These and other variations are described in the individual reports that follow. One hundred and thirty-seven pediatric residents and 75 family medicine residents completed

their program's PPHE model. Another 62 residents who were at different stages of the residency process when the program began completed parts of the curriculum.

Number of Primary Care Residents Trained 2005-2008

St. Barnabas Hospital	Pediatric Residents: 27	Family Medicine Residents: 18
Stony Brook University Hospital [1]	Pediatric Residents: 62	Family Medicine Residents: 28
Winthrop University Hospital [2]	Pediatric Residents: 48	
St. Elizabeth Hospital		Family Medicine Residents: 29
Total Number Trained	**137**	**75**

[1] Another 26 residents completed part of the PPHE curriculum at Stony Brook
[2] Another 36 residents completed part of the PPHE curriculum at Winthrop

Didactic Lectures

All grantees were required to provide the four basic PPHE Curriculum lectures. The project officers or their designees designed the lectures following a general outline, fitting the contents to complement other elements of their residency curriculum. The *Introduction to PPHE* presentation described the program goals, curriculum, and expectations for participation. This session allowed residents to ask questions and understand how PPHE could contribute to their knowledge, skills, and attitudes about working with families and individuals with developmental disabilities. Some grantees prepared detailed resident manuals and PowerPoint presentations to provide complete information about the program.

The other three presentations were specific to the goals of the program. The session on *Assessment of Developmental Disabilities* focused administration and interpretation of the Denver II assessment tool but often covered other assessment tools, including the MCHAT and parent evaluation tools (i.e., PEDS, Ages and Stages). The Denver II is often taught in pediatric residency programs but is new for family medicine, which tends to prefer the parent evaluation tools. Some grantees provided Denver II kits to their residents.

Legal Aspects and Accessing Services for Children with Disabilities described the legislation that authorizes services and protects the rights of individuals with developmental disabilities, with particular attention to the Individuals with Disabilities Educational Act that provides for screening and services for children with developmental disabilities. This lecture provided a framework for the community agency visits. Residents learned how to make referrals and follow up with Early Intervention programs, observed a variety of health care professionals providing services in different locations, and often visited schools to observe children with disabilities in integrated classrooms.

The *Doctor-Patient-Family Communications* lecture augmented the residency programs' skill development process on patient-centered communications, including interviewing skills appropriate for parents and children. Cultural values affecting the family's attitudes and ability to care for a child with disabilities were addressed.

Each of the four grantees in Phase I had to adjust their original plans for offering the didactic lectures. All experienced difficulty scheduling lectures at times when most residents could be present. Solutions included: Taping the didactic presentations which were then made accessible through the hospital's Blackboard or other web-based system; making the PowerPoint and lecture handouts easily available; designating specific times on the residents' schedule for PPHE activities and using other designated times (i.e. noon conference or grand rounds) for PPHE activities.

Despite scheduling problems, all four grantees added lectures to their PPHE programs. PPHE programs in pediatric residencies had the advantage of multiple lectures (i.e. noon conferences, grand rounds) on related pediatric topics. Family medicine residency programs added lectures to augment the PPHE curriculum. OMRDD provided additional didactic lectures open for both pediatric and family medicine residents.

Following is a list of lectures added to the four required lectures.

Didactic Lectures Added by PPHE Grantees

St. Barnabas

- Medical Care of a Child with Developmental Disabilities
- Breaking Bad News
- Accessing Community Resources
- Navigating the Educational System (and legal Aspects)
- Specific Developmental Disabilities, including Autism Spectrum Disorders, Cerebral Palsy, and Speech and Language Disorders
- Transitional Services for Children with Developmental Disorders into Adulthood
- People First Language

Winthrop

- Asperger's Syndrome
- Prader Willi Syndrome
- Autism Spectrum Disorders
- Giving Bad News
- School is over: What do we do with a child with a developmental disability?

St. Elizabeth

- Understanding Developmental Disabilities
- Willowbrook
- Spina Bifida and its Developmental Disability Implications

Stony Brook

- Sensory Integration Disorder
- Developmental Disabilities through the Lifespan-including Biopsychosocial Model of Evaluation

Community Medicine Case Presentations

Case presentations proved to be an effective means for sharing information about home and community agency visits and specific medical diagnoses. Some grantees scheduled two or three case presentations a year, others scheduled more.

Community Medicine Case Presentations

Program	Most Common Setting	Organization of Presentation	Attention to Medical and/or Social Information
St. Barnabas Pediatric Residents	• Integrated into regular lecture schedule • Noon Conferences • Ambulatory Pediatric lectures time slot • PPHE residents excused from Morning Report for OMRDD lectures	• Open to all residents, attendings, medical students • Occasional parent and/or community agency participation	• Mix of medical and family dynamics • Usually augmented with reviews of medical literature, PowerPoints
St. Barnabas Family Medicine	• Morning conferences	• Open to all residents, attendings, medical students • Occasional parent and/or community agency participation	• Mix of medical and family dynamics • Usually augmented with reviews of medical literature, PowerPoints
St. Elizabeth Family Medicine	• First Friday of the month at designated PPHE meetings • 6 (1 hour) scheduled directly after morning report • 5 (2 hours) during excused morning report time	• Presented to other PPHE participants, the Behavioral medicine Director and the PPHE Program Director • Pediatric Director	• Parents and community agencies not usually present • Mix of medical and family dynamics • Augmented with medical research
Winthrop	• Noon conferences	• Open attendance	• Often parent and community agencies participated • Mix of medical and family dynamics • Not usually augmented with medical research
Stony Brook	• Resident meetings and noon conferences	• Open attendance	• Parents and community agencies did not often attend • Mix of medical and family dynamics • About half included additional medical information

Small Group Discussion and Resident Reflections

Both small group discussions and resident reflections are accepted pedagogic techniques for integrating and interpreting learning experiences. Yet, both techniques were sometimes difficult to integrate into the busy schedules of medical residents. In pediatric residency programs, most PPHE activities were conducted during a designated rotation, either the developmental and behavioral rotation or the community medicine rotation. The small group discussions were interwoven as part of rotation expectations. Sometimes the small group discussions were conducted during or after the community medicine case presentations.

Effective ways to acquire resident reflections were: Verbally during didactic lectures, case presentations, or one-to-one during a rotation; written in response to question prompts via email, home visit reports, or a secure web site.

Small Group Discussion and Resident Reflections

Program	Small Group Discussions	Resident Reflections
St. Barnabas	• One to-one with PPHE project director • Incorporated as part of Medicine Case Presentation	Written responses to questions
St. Elizabeth	• Discussed PPHE activities during one-week Behavioral/Pediatric Medicine rotation • Discussed at monthly PPHE meeting of residents • Issues addressed during role-playing with Behavioral Medicine Director	Found written reflections difficult and changed to verbal discussions at monthly meetings or at case presentations
Winthrop	• Incorporated as part of Medicine Case Presentations • Periodically with residents who completed both the home and agency visits	Written response to questions on secure web log
Stony Brook	• After Medicine Case Presentations or after lectures, or during departmental resident meetings	Verbal

PPHE Materials

Each grantee developed PPHE informational materials specific to the community each serves. These materials included brochures for parents, physicians, clinics, and community agencies; letters to physicians; parent-partner application forms; home and agency interview schedules; and resident reflection questions/forms. St. Barnabas Hospital made these materials available in English and Spanish.

The grantees also developed materials for their residents, including orientation manuals and PowerPoint presentations. Versions of the four required didactic lectures were shared among the PPHE grantees, allowing the group to fine- tune presentations.

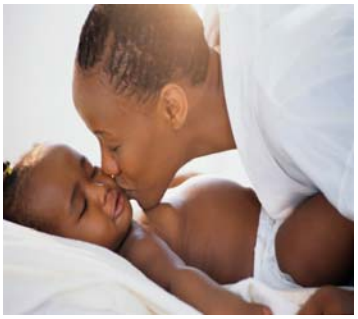
WINTHROP UNIVERSITY HOSPITAL

Project Director: *William Bryson-Brockman, PhD. Chief, Behavioral Pediatrics*

Approach to PPHE Curriculum

Each year, 16 first year pediatric residents actively participated in the PPHE curriculum. Residents from all three years (48 in all) participated in the lecture series in each of the three years, but only first year residents were actively trained during their behavioral-developmental pediatrics rotation. Therefore, between 2005 and 2008, all first year residents received the full PPHE curriculum. An additional 32 residents, who were PGY2s and PGY3s when PPHE started, received many aspects of the curriculum (lectures, small group discussions, case presentations) before they graduated.

During their month-long behavioral-developmental pediatrics experience, each resident was introduced to the curriculum on the first day of the rotation and oriented to the experiences that would occur. Each resident visited the Variety Child Learning Center three times with the following schedule: First day, introduction and tour of the facility; second day, observe while in the classroom taking data on a target child with a developmental disability; and third day, meet with social work and support personnel to discuss the impact on the family of a child with a developmentally disability. Each resident also visited Abilities (a division of the National Center for Disability Services), a school for children with disabilities, to see how a pediatrician works in this environment and to learn about services for this population.



Getting Ready to Implement PPHE

Having six months to plan the details of implementing the PPHE program was very helpful in setting up the necessary systems. The project director was able to hire a part-time coordinator/secretary, outfit her with a computer and space, prepare pretests, conduct meetings with faculty and outside agencies, and discover a free online web log to record resident experiences. Although some difficulties in scheduling lectures and small group experiences were expected, the project director was able to control the majority of each resident's schedule during their month on the behavioral-developmental rotation. This flexibility contributed to successfully managing the PPHE curriculum. Residents were introduced to the PPHE curriculum at a special session just prior to starting the residency program. Winthrop's program focused on first year residents (interns), who were pretested prior to any PPHE lectures. Orienting residents prior to the official start of residency seems to be the best time to approach them in one place at the same time.

Challenges

Lecture attendance. A difficult challenge was to ensure that all residents attended the series of PPHE lectures. Winthrop's approach to the problem of unavoidable absences was to videotape lectures for residents to view at a later time. Tracking down residents and ensuring their compliance was often difficult and time consuming. Although some of the impact of a lecture is lost when not experienced live, videotapes proved to be the best option.

Use of time at home visit. Another challenge was to ensure that each resident had enough time with the parent-partners and with the child with a developmental disability to complete a comprehensive interview. At the second home visit, residents completed a short assessment of the child's adaptive behavior using

the SIB-R (Scales of Independent Behavior-Revised). This added variety to the visit and gave the resident experience with the SIB-R.

Community Agencies

Prior to implementing the PPHE curriculum, Winthrop had some tentative relationships with several community agencies. These relationships have been strengthened significantly by Winthrop's three year PPHE commitment. Both Winthrop and these agencies would feel a great sense of loss if the collaboration were discontinued. The Variety Child Learning Center has promoted its relationship with PPHE in newsletters and presentations to the professional community. Because of the relationship with Winthrop, Variety Child Learning Center obtained a grant last year through their local state senator to further the training of pediatric residents, ensuring that Winthrop and Variety Child Learning Center will continue to work together.

Parent Recruitment

Parent recruitment has taken some effort and some luck. Project director, Dr. Bryson-Brockman, attended parent meetings at Variety Child Learning Center, Genesis School for Autism, Nassau Suffolk Services for Autism, Plainedge Special Education Parent Teacher Association, and a parent support group led by a parent partner. Each meeting led to a list of willing parents, which Dr. Bryson- Brockman utilized to select parent-partners. He personally spoke with many of these parents and interviewed them further before making an appointment for each resident. Dr. Bryson-Brockman also approached several families in Winthrop Hospital's pediatric waiting room to tell them about PPHE and invite them to participate. Local physicians contacted Dr. Bryson-Brockman from the beginning to recommend families for inclusion in PPHE as well. Overall, with some personal effort, parent-partners were not difficult to find, given that a large number of children who have developmental disorders are seen at Winthrop.

Clinical Experiences

Primarily, clinical experiences related to the PPHE grant were conducted at the continuity clinic or when residents saw patients with Dr. Bryson-Brockman. However, resident's visits to the National Center for Disability Services and the Variety Child Learning Center also encompassed some direct clinical interactions with children. Each administration of the Denver II developmental screening tests was observed by Dr. Bryson-Brockmann and each was documented in Winthrop's New Innovations website for residents. Residents treated a variety of patients during the three years, including children with Down syndrome, Prader-Willi syndrome, Autism Spectrum disorders, and mental retardation.

Lessons Learned

Three years experience with the PPHE program has convinced the project director that the curriculum is very well designed, with components that support each other and that are sustainable given the large numbers of families with children who have developmentally disabilities. 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.

Best Practices

- The repetition of lectures is important. The residents did not complain about the lectures as might be expected. Residents have to learn so much information that the repetition seems to be helpful.

- The most important factor for success of PPHE at Winthrop was the control the project director had over the scheduling of the resident's experiences during the month-long behavioral-developmental pediatrics rotation. Most of the PPHE curriculum (except the formal lectures) was accomplished during these months, as were visits to the Variety Child Learning Center, parent-partner interview, clinical visits with the project director, and completion of Denver II screening tests. Further, the chief resident supported PPHE by being flexible in scheduling lectures with short notice. Having a relatively small number of 16 residents per year (48 total) allowed for a more personal approach.

- In the third grant year, residents completed a short assessment of the child's adaptive behavior using the SIB-R (Scales of Independent Behavior-Revised) during the home visit. This gave the resident experience with the SIB-R and added some variety to the home visit.

- Another factor for a successful PPHE program is a personal commitment by the director/ leader of the program and the development of personal relationships with community agencies and other professionals in the developmental disability field. These relationships helped to recruit parent-partners and outside lecturers, thereby increasing the "specialness" of this program. The project director attended many community meetings to spread the word, and this helped foster ongoing and hopefully lasting relationships.

- Each resident was videotaped doing a patient interview. The videotape was later reviewed with the resident, who selected one interviewing skill to improve.

- Each resident was given a Denver II screening kit.

Sustainability

The PPHE curriculum is integrated into the Winthrop pediatrics residency program and will remain part of the behavioral-developmental rotation. The strong ongoing relationships with community agencies and parents will enable maintenance of this special program.

Dr. Bryson-Brockman believes that PPHE is a successful program that can be sustained at Winthrop-University-Hospital with some modifications. Winthrop University Hospital has been supportive of bringing in guest lecturers, especially at grand rounds, to talk about developmental disabilities. It is possible that Winthrop can arrange for Denver II kits for each resident, but the program is still looking for funding to pay parent-partners to participate. Offering a small stipend recognizes the key role of parent partners in helping residents learn important lessons about the home lives of children with developmental disabilities. Winthrop's grant support personnel were especially helpful in fulfilling all the grant requirements, and the hospital's administration has been very supportive. Variety Child Learning Center has agreed to continue accepting Winthrop's pediatric residents three times a month, even without reimbursement.

ST. ELIZABETH MEDICAL CENTER

Project Team:

- Brad Bennett, PhD, Director of Behavioral Medicine; Licensed Psychologist
- Collene Brownell, Program Manager
- Janine Carzo, M. S., Administrative Director of Medical Education, PPHE Project Director
- Nicole Cocomazzi, Social Services Coordinator
- Sanjeev Vasishtha, MD; Board Certified, American Board of Pediatrics

Approach to PPHE Curriculum

Over the course of three years, the Family Residency program at St. Elizabeth Medical Center implemented the PPHE Program for 27 second year residents. The PGY2 residents were targeted to be involved with the PPHE to augment experiences from their first year of residency and to prepare them to share their PPHE experiences with fellow residents and patients in their third year. PPHE processes and materials were purposefully designed to support the Medical Home model. Specific to the PPHE curriculum:

- 27 families were recruited to participate in the PPHE program through communication with the PPHE Program Coordinator.

- PGY2 residents participated in a newly created behavioral medicine/pediatric rotation with Dr. Vasishtha and Dr. Bennett to gain clinical, psychosocial, and direct experience with individuals with developmental disabilities.

- The program coordinator accompanied residents on family visits to facilitate the visit and ensure the resident's safety and comfort.

- A specific time each month was planned for PPHE activities so residents and coordinators could better manage their time.

Getting Ready to Implement PPHE

The PPHE project leaders expected that there would be a good amount of time involved in implementing this program and were uncertain how positive the impact on the residents might be, but felt strongly that if the program was conscientiously developed, PPHE would be a success. Participating in PPHE proved to be all of the above, and everyone who participated had a positive experience.

During the implementation of the PPHE program, many individuals were involved. Other than the above named coordinators, the Family Residency Program Director, Dr. William Jorgensen, Family Medicine Director, Dr. Mahesh Padmanabhan, the entire Family Residency Staff and Faculty, St. Elizabeth Medical Center Faculty and Administrators, PGY1 and PGY3 residents contributed to this successful project. PPHE program materials were distributed and updated, as needed. Progress reports were given to hospital personnel and community agencies.

The residents were introduced to the PPHE program each year through a formal orientation. 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 such as *Bright Futures: Behavioral and Pediatric.* Throughout the three years, residents were always given an opportunity to express their opinions and recommend changes in the program.

Challenges

Introducing PPHE. Adding to residency requirements is always difficult, as the PPHE staff found out in the first year. Resident resistance to PPHE was reduced in grant years two and three as the project team more actively solicited resident input on processes, streamlined requirements, and designated protected time for PPHE activities. St. Elizabeth's original PPHE design included a 360° evaluation process to identify issues and make corrections.

Project coordination. Due to staff time restraints, other work assignments, staff transfers, and unexpected staff absences, staff familiar with PPHE was not always available. PPHE project leaders recognized the need to have additional personnel knowledgeable about PPHE. A talented program coordinator was promoted within the Family Medicine program after the first grant year and trained her replacement. This step provided for staff coverage when a designated person was not available for PPHE activities.

Availability of clinical experiences relating to developmental disabilities**.** To insure the availability of quality clinical experiences, residents participated in a newly created behavioral medicine and pediatrics rotation as well as additional clinical experiences with Dr. Vasishtha and Dr. Bennett. This new rotation was approved by the Graduate Medical Education Committee based on the identification of goals, objectives, and evaluation criteria consistent with the PPHE curriculum.

Residents spent time at Dr. Vasishtha's practice to increase their interaction with children with developmental disabilities. Residents also requested parent permission to obtain their assigned child's medical records from their private physicians. The information obtained in the child's medical records was found to be valuable because residents gained an understanding of the care of children with developmental disabilities from an ongoing medical perspective.

Resident reflections. Residents strongly resisted journal entries regarding their points of view about family visits and the program in general. However, residents agreed to document their opinions as part of their medical case summaries.

Scheduling issues. Because the residents had difficulty incorporating PPHE activities into their usual schedules, specific time for PGY2 residents were set for the first Friday of the month following grand rounds**.** During this time, residents conducted community agency interviews, presented their medical case summary and viewpoint of the family visit, heard didactic lectures, participated in role playing, and discussed various issues about PPHE.

Home Visits; Arranging home visits was a challenge until the process was standardized. The PPHE coordinator started scheduling home visits for residents when it became apparent that the residents were having difficulty scheduling their own visits. Half of the residents participated in home visits during the developmental and behavioral rotation in the fall and the other half of the residents did their visits during the community medicine rotation in the spring. The PPHE Coordinator accompanied residents on the home visits to ensure resident comfort and safety.

Community Agencies

The Family Medicine Center at St. Elizabeth's Hospital has always been a strong presence in Central New York. When community agencies were contacted, residents were welcomed to visit. St. Elizabeth's

hosted a community partners committee for the first grant year but discontinued these regular meetings due to time constraints for all of the organizations in the group. However, project staff maintained cordial relations with the community partners.

The response from the community service agencies to PPHE has been supportive and encouraging. When planning started for PPHE in the spring of 2005, project leaders conducted a Community Needs Assessment. This increased the residency staff's familiarity with community agencies and their services. It helped to customize the PPHE curriculum for the Utica community. The survey also contributed to the development of criteria for recruiting parent partners.

Agencies were willing to share information about PPHE with families and to share information with residents during their site interviews. Agencies also volunteered to help with didactic lectures. Interestingly, during the first two years of the PPHE, residents expressed dissatisfaction with agencies' didactic lectures, reporting that the agencies were explaining their services instead of presenting the required lectures. In response to this, clinicians and administrators from the St. Elizabeth Medical Center assumed the didactic lectures during the monthly meetings, morning report, and grand rounds.

There has been a definite advantage having the community agencies involved in this program. The agency support has allowed residents to become aware of resources available for their current and future patients. Even if residents establish practices in other communities, they are aware of the kinds of agencies and services likely to be in every community.

Parents Recruitment

Parents were recruited through communication with St. Elizabeth Medical Center staff via email, the *Elizabethean* (the hospital's newsletter), and staff meetings. Community agencies and local elementary, middle and high schools were contacted, and articles were placed in the local newspapers to reach the greater community. The response to this outreach encouraged a wide variety of families from throughout Oneida County to participate. Different families were involved each year, fulfilling the project leaders' interest in maintaining diversity.

PPHE staff designed and later simplified the parent informational brochure and parent application forms to collect the necessary basic information and to accommodate parents' literacy skills. Parents signed an Informed Consent form and used hospital approved parent stipend information materials. A stipend was provided for the families throughout the three-year program. Once families completed their family visit and evaluations, a quarterly stipend was distributed to families. The St. Elizabeth Family Medicine Center feels strongly that some families would participate in the program without a stipend. Many families have expressed to the PPHE coordinator their need to "tell their story and educate a doctor."

Each PGY2 resident was able to visit a family at least once, with the majority making two or more visits. Residents not able to visit their families a second time contacted families by phone. Family visits lasted from 45 minutes to as long as 2 hours. While there was no minimum or maximum time requirement for visits, residents were provided with questions as a guide to learn about the family. The length of the visit depended on willingness of families to communicate with residents and vice versa.

Clinical Experiences

Residents gained clinical experience during the behavioral/pediatric medicine rotation and when present at the Family Medicine Center. During the rotation with Dr. Bennett, residents participated in psychosocial evaluations and had other hands-on experiences. Additionally, PGY2 Residents rotated with Dr. Vasishtha in his practice and during their third year at the Family Medicine Center when the Pediatric Clinic was scheduled.

Best Practices

- Involving the residents in the planning process for this type of residency program change is critical. Project staff found the residents honest in their critiques and helpful in fine-tuning the program.

- Residents enjoyed the role-playing sessions that Dr. Brad Bennett facilitated during the PPHE monthly meetings. The majority of residents were not familiar with home visits. Foreign-trained residents found the role-playing sessions particularly helpful.

- Didactic lectures presented by St. Elizabeth clinicians and faculty proved beneficial to residents, as evidenced by their lecture form reviews and attention during the presentations.

- Scheduling a specific meeting time on the first Friday of each month dedicated time for PPHE in the resident's hectic schedule. It assisted the Program Coordinators with meeting requirements of the program and was less pressured than not having a set schedule.

- Splitting resident home visits between the fall and spring simplified the process.

- The PPHE grant prompted St. Elizabeth to take two actions that might not have taken otherwise: (1) DDPC's Person First Language handout was distributed to all residents and faculty; and (2) the hospital offered a session of Cultural Diversity and Developmental Disabilities.

Sustainability

The PPHE team leaders - Family Medicine Program Director, Administrator of Medical Education, Behavioral Medicine Director and Pediatric Director - strongly advocate continued use of PPHE in the Family Medicine program, although additional funding resources have not been pursued. The PPHE Program will be integrated into the PGY2 residency year in the following ways:

- PPHE Orientation will be given during July for PGY2 residents.

- Friday meetings dedicated to PPHE will take place five to six times a year instead of 12 per year.

- PGY2 residents will rotate in behavioral and pediatric medicine and during this time will visit community agencies as well as a family to interview.

- Didactic lectures will be presented at morning report and grand rounds for all residents.

PPHE was a positive educational experience for both the residents and coordinators. Many of St. Elizabeth's residents were foreign born and have never interviewed or interacted with a child living with a developmental disability. One resident noted after a family visit, "that family taught me to count my blessings, something I have forgotten to do because I am always busy."

STONY BROOK UNIVERSITY MEDICAL CENTER

Project Director Susan Guralnick, MD **Project Coordinator** Susan Lesco, QMRP

Approach to PPHE Curriculum

In order to ensure that all of the physicians had the opportunity to benefit from the PPHE curriculum throughout their residencies, Stony Brook offered the complete program every year for three years. With this approach, residents who were not able to fully complete all elements of the project in the first year were able to participate in the following two years. Those who participated in year one, assisted the incoming residents in the following years. The configuration of resident participants was as follows:

Year 1: 13 PGY-2 and PGY-3 Family Medicine residents; 14 PGY-1 Pediatric Residents
3 PGY-2 & PGY-3 Pediatric Residents

Year 2: 7 PGY-2 Family Medicine Residents; 14 PGY-1 Pediatric Residents;
6 PGY-2 Pediatric Residents

Year 3: 8 PGY-2 Family Medicine Residents; 18 PGY-1 Pediatric Residents;
7 PGY-2 Pediatric Residents

Getting Ready to Implement PPHE

Stony Brook had several expectations upon receiving the DDPC Parent Partners grant. Project leaders looked forward to receiving curricular materials that would facilitate educating the residents in the care of children with developmental disabilities. The intention was to incorporate these PPHE materials into the established curriculum on children with developmentally disabilities and their families.

The PPHE staff looked forward to the opportunity for the pediatric and family medicine residents to meet with families in their home environments, where they could both see and learn about the life of a family with child who has a developmentally disability. Additionally, the project staff welcomed the opportunity to form educational relationships with agencies involved with individuals with developmentally disabilities.

Led by the Pediatric Residency Director, Susan Guralnick, MD, Stony Brook first began implementing PPHE by enlisting the assistance of faculty members from both the departments of pediatrics and family medicine. Dr. Guralnick and Dr. Jaffe of Family Medicine arranged for both pediatric and family medicine meeting and conference days to take place at the same time.

The faculty introduced the program to residents during these coordinated times. The project coordinator prepared and distributed a manual and CD that included the history, mission and goals of the project, schedules and timelines, and required pre/post tests and evaluations. The coordinator also set up a dedicated web page and prepared and distributed public outreach materials, including brochures, announcements, and parent applications.

The PPHE team partnered with Stony Brook's Cody Center for Autism and Developmental Disabilities. Together, Dr. Guralnick, Dr. Janet Fischel, Dr. Arnold Jaffe, Dr. John Pomeroy, and Ms. Susan Lesco took an active role in presenting didactic lectures, observing both clinical and home visits, and conducting small group discussions.

Challenges

Clarity of PPHE goals and expectations. The PPHE program coordinator developed a detailed PPHE Resident's Manual after witnessing some reluctance and confusion from residents about expectations in the first year. While part of this may have been a reaction to something new being added to the residency curriculum, the program leaders felt clarity of program goals and expectations would add to the program's effectiveness.

Need for flexible participation in PPHE. In the early part of the project, Stony Brook had expected to mandate participation for all residents. Occasionally, a resident would need to complete a PPHE component early in the following year. The project leaders' plan to incorporate all elements of the curriculum into residents' schedules worked better in the pediatric residency than in the family medicine residency.

Institutional changes unrelated to PPHE. The medical center encountered a number of unexpected changes in personnel, including changes in faculty members participating in the project. These changes required reassignment of some responsibilities.

Scheduling. After adjusting to organizational and curricular changes, the team's primary challenge was scheduling. To offset this challenge, the team presented lectures in multiple locations at different times and posted them on the residents' secured web site. Parent- partners hosted more than one resident at a time and spoke with residents at off-campus clinics. Several residents visited off-campus sites together.

Proximity. Experience implementing PPHE in two residency programs confirmed that each program requires its own director onsite. The pediatric and family medicine programs and clinics are housed at separate locations throughout Long Island, which meant that communications were sometimes delayed. The value of onsite directors is underscored by the fact that PPHE curriculum components may need to be modified since pediatrics and family medicine follow different Residency Review Committee program requirements.

Assigned rotation for PPHE activities. Family medicine created a community medicine rotation, during which PPHE home and agency visits could take place. Pediatrics used its existing community medicine rotation for this purpose. Asking residents to make these visits on their own time, given other residency requirements, is burdensome.

Accompanying residents on home visits. A family medicine faculty member accompanied residents on home visits to observe the interview process and interaction with the family. This allowed the faculty member to provide positive reinforcement or constructive criticism and to identify topics for further discussion with the resident. Staff from the Medical Home office at St. Charles accompanied pediatric residents on home visits and participated in evaluating the interviews.

Community Agencies

In addition to collaborating with the Cody Center for Autism, Stony Brook also worked closely with the Mary Haven Center of Hope, Just Kids, St. Charles Hospital, and the New York chapter of the Advocates for High Functioning Autism. Although the department of pediatrics had existing relationships with collaborating schools and agencies, they were strengthened with the introduction of PPHE. Both pediatric and family medicine residents had the opportunity to become involved and interact with new families in their natural environments.

Simultaneously, Dr. Guralnick was co-directing a Medical Home project with another Long Island facility, St. Charles Hospital. By integrating the efforts of both projects, PPHE residents obtained additional and more diverse experiences.

Dr. Guralnick and Ms. Lesco were visited by public health specialists from the American Academy of Pediatrics Medical Home Services at two locations. Stony Brook introduced the public health specialists to the PPHE program. They expressed interest and enthusiasm for the PPHE project. As a result of this collaboration, staff from the Medical Home office at St. Charles accompanied residents on home visits and participated in evaluating the interviews.

Parents Recruitment

Stony Brook recruited parents from collaborating agencies as well as from its own ambulatory care clinics located throughout Long Island. Although no stipend was offered, many families volunteered to host residents. Interviews lasted approximately one and a half to two hours, depending on the time of day. Due to the difficulty scheduling mutually convenient times for interviews, only a few families continued to volunteer throughout the program. However, those who remained were invested in assisting with the project.

The Medical Home nurse, Michele Mackey, is also a parent of a child with developmental disabilities. Ms. Mackey hosted PPHE residents at her home and has offered to continue doing so in the future.

Clinical Experiences

The Residents' clinical experiences took place at Stony Brook University Medical Center through the resident continuity care clinics as well as the inpatient services, the emergency department, and outpatient subspecialty clinics. In addition, residents interacted with children who have special needs during their community medicine and behaviorial- development rotations. This included experiences through the early intervention program and special needs school visits.

Best Practice

- One key to the success of PPHE at Stony Brook has been the efforts by PPHE leaders to inform and collaborate with other university offices and schools. Stony Brook University Hospital's Chief Operating Officer learned about PHE during a visit to the department of pediatrics. Presentations on PPHE were made to directors and members of the Department of Health Care Policy and Management, the Department of Psychiatry, and the schools of Medicine, Public Health, Health Technology Management, and Social Welfare. PPHE leaders also presented lectures on curriculum topics to the OMRDD Long Island Developmental Disabilities Service Office Family Support Coordinators, the Long Island Region Parent-to-Parent of NY State, and the New York Chapter of the Advocates for High Functioning Autism.

  In the spring of 2007, the Dean of the Medical School convened a meeting to discuss the education of medical students, primary care residents, and hospital staff on working with individuals with developmental disabilities. Faculty leaders were assigned responsibility for specific areas with the

goal of making services at Stony Brook more adaptable, individually focused, and accessible to people with developmental disabilities. Work on this major project is continuing.

- The most effective ways to accomplish total participation are 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. The annual repetition of didactic lectures was helpful in assuring that each resident class was exposed to the material. The residents found it helpful to have a preceptor present at the home visits to help them to focus on key issues they might otherwise overlook during the visit.

- Some of the residents presented concerns about the privacy of people participating in the project. Project staff reiterated that each participant's privacy was strictly protected according to HIPAA regulations. Each family participant completed an application and signed consent to take part in the project.

Sustainability

Stony Brook has several ways to integrate PPHE into its residency programs. A key step is to incorporate home visits into the community medicine rotation, which all residents experience. Visits to special needs schools and early intervention centers, as well as early intervention program home visits will be continued in the community medicine and behaviorial-development rotations that all residents also experience. The didactic lectures have been integrated into regularly scheduled conference days.

During the third year of the PPHE program, Dr. Pomeroy and Ms. Lesco incorporated elements of the PPHE project's curriculum into the developmental disabilities portion of the Department of Psychiatry's curriculum entitled Psychiatry in Medicine. As a result, important segments of Parent Partners in Health Education will be added to this required curriculum, starting in the 2008-2009 academic year. This effort will be augmented by the hospital's work to improve its education of medical students, residents, and hospital staff on working with families and individuals with developmental disabilities.

Funding is not required for these sustainable features of the PPHE program. Stony Brook's continuity clinics emphasize the importance of parent partnerships in the care of individuals with developmental disabilities so PPHE becomes a part of the everyday resident curriculum of patient care.

ST. BARNABAS HOSPITAL

Project Directors: Paola Carugno, MD and Candace Erickson, MD

Approach to PPHE Curriculum

The PPHE curriculum was incorporated into the training of the Pediatric (Peds) and the Osteopathic Family Medicine (FM) residency programs of St. Barnabas Hospital (SBH) in July 2005. All three years of residency training were involved in PPHE. Some components of the training were specific for each year of training and other components, i.e. lectures, were repeated each year.

During the first year of PPHE, the same curriculum was created for the family medicine and the pediatric residents. It soon became evident that these curricula needed to be tailored to the specific training styles of each program. Beginning in the second year of implementing PPHE, each program has had a somewhat different track.

The first year residents of both programs accompanied a nurse during home visits to children with disabilities. This served several purposes: 1) It provided the initial exposure to the homes and the community where St. Barnabas' patients live; 2) the visiting nurse, an experienced health care provider, modeled appropriate in-home professional behavior and sensitive interviewing skills; and 3) the residents experienced that they were both safe and welcomed in a family's home. The pediatric residents were excused for one-half day from their well baby rotation and the family medicine residents were excused from one-half day of outpatient FM rotation for the home visit.

During both the second and third residency years, the pediatric residents had a four-week rotation of developmental and behavioral pediatrics/pediatric neurology. The schedule for this rotation was set by the developmental pediatricians who were also the project coordinators of PPHE. The partner family was contacted, and the family and community agency visits were added to the schedule of the rotation. During the third year, the physicians visited the same partner family they met the year before. This allowed them to observe the changes after a year of development and services. During the third year, the physicians visited different agencies that served the same family or that served families with children who have similar disabilities. This permitted them to see a broader spectrum of available community services for the particular type of disability. In addition, during the third year rotation, each resident presented a community pediatrics lecture. The resident presented the child and family's story, elaborated on a topic related to the child's disability, and shared reactions to and reflections on experiences with the family and the servicing agencies. This lecture was attended by the other pediatric residents. Those who had also done home and agency visits often compared and contrasted their experiences with those being presented.

After the first year of implementing the same curriculum for both programs, separate PPHE tracks were developed, each more tailored to the specific needs and schedule of the residency programs. The pediatric residents program remained as described above with the addition of several seminars dealing with the availability of and transition to services for adults who have a developmental disability.

The family medicine residents asked for more exposure to pediatric training as well as to become more comfortable with the medical care of adults with developmental disabilities. A project coordinator was assigned from the FM department. Starting in the second year of PPHE, all family medicine residents

were matched as the primary care providers for at least one adult with a developmental disability from a group home who receives medical care at the St. Barnabas Hospital. The FM residents continued to follow their patient for the duration of their residency training. The community residence became a partner agency and the FM doctors also began visiting a day program and a residence, usually that of their matched adult with a developmental disability.

Beginning with the third year of the PPHE grant, the second year FM residents spent one-half day at a special education preschool and attended one-half day in the developmental pediatrics clinic. The third year FM residents began visiting the Bronx medical clinic of the Association for the Help of Retarded Children (AHRC), a specialized medical clinic for adults with developmental disabilities. Condensing these activities into a full day for the FM PGY2s and PGY3s has increased the rate of completion of the PPHE curriculum to 100 percent.

More lectures were incorporated as community agencies offered them. Staff from OMRDD, Medicaid Service Coordinators, and even a parent-partner offered to join these lectures.

Project directors wanted to maximize the exposure of the residents to the PPHE curriculum by including components of PPHE in each year of residency training. Since the program has only existed for three years, residents received different levels of exposure to PPHE. One group of residents completed all three years; two groups completed two years and one group of PGY1s and PGY3s finished one year. During grant year 2 and grant year 3, approximately two thirds of the residents had also been exposed to components of PPHE during the previous year(s). In total, 18 family medicine and 27 pediatric residents were exposed to PPHE over the 3 years.

Getting Ready to Implement PPHE

After learning that the St. Barnabas Hospital proposal for PPHE was accepted by DDPC, the PPHE project directors met with the chairmen and residency program directors of each department. Soon after, presentations on the PPHE curriculum were given at faculty meetings for each department. There was an enthusiastic reception of the program. At the time the department of pediatrics had been educating pediatric residents about individuals with developmental disabilities, but the residents were not being exposed to the families, homes, or communities of these individuals. The FM 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.

The PPHE project directors presented the Illinois curriculum to the department and hospital administrators, explaining that they would be customizing the curriculum. Having the defined curriculum made it easy to get support for the project.

PPHE was introduced to all the residents of both residency programs as part of their core lectures at the beginning of the academic year. This introduction was repeated every year at the initial developmental pediatric lecture for each training program. Pre-test questionnaires were also collected from all the new participants in PPHE. All the PPHE lectures were newly added educational lectures for the FM program and were specifically scheduled with the Chief Residents.

Challenges

Adding to the residency curriculum. Incorporating a new curriculum as an “add-on” to already full training programs was a very challenging, time and energy consuming experience. The project directors quickly learned from the first year of the project that everything, from the schedule of lectures to the

interviews, needed to be fully integrated into the existing schedule of each training program to make PPHE a successful and sustainable educational curriculum.

Scheduling visits. Finding time to schedule the parent interviews and agency visits, expecting the residents to contact the families on their own, keeping track of the activities completed and due was very time consuming. The project directors made adjustments to the processes so that by the third year of the project, the PPHE activities were more efficiently scheduled.

Reflections. Gathering the residents' personal reflections was a challenge, mostly during the first year of PPHE. During that initial year, the residents were being asked to simply write about their personal experience. The results varied greatly: A few residents returned reflections of how they felt about the experience, some just summarized the parent's responses to their questions, some wrote a medical report and others did not write any reflections at all. Starting in the second year, residents were given a one-page template for the reflections with specific questions about the experience. This led to a significantly higher completion rate for the personal reflections and the inclusion of more information about the residents' reactions to and insights gained from the experience.

Evaluation. Lengthy pre and post-test questionnaires, required for the uniform evaluation of all of the PPHE projects, made it hard for the residents to return these forms promptly. The lessons learned from this challenge are to designate a specific time for evaluation activities and to keep the evaluation instruments as short as possible.

Small group discussions. Small group discussions were difficult to schedule, whereas one-to-one debriefings were more easily accomplished and preferred. Since the residents shared and compared many of their personal impressions during their community medicine presentations, doing one-to-one debriefings immediately after the visits and incorporating the small group discussions with the community medicine presentations seemed appropriate and worked well.

Community Agencies

The initial community partners were agencies already collaborating with St. Barnabas in patient care or resident education programs. These relationships were strengthened and the agencies' involvement in resident education was expanded as the project developed. Since the project directors felt that it was important, when possible, for the residents to visit agencies that served their partner family, other agencies were invited to participate as the families who were served by them were recruited. The response from the different agencies has been overwhelmingly encouraging. When a well known and established special education preschool was initially visited, staff members reported that no physician had ever visited them before.

Most agencies were supportive and continue to be so. They provided staff time and resources to support PPHE. In general, community agencies that serve children and adults with developmental disabilities are very supportive of any effort that will lead to physician's education and better outcomes for the individuals they serve.

Parents' Recruitment

An attempt to recruit parents from the pediatric clinics was initially done by asking general pediatricians to invite families with children with special needs to participate. At St. Barnabas Hospital, a large percentage of the children with disabilities are followed by the two developmental pediatricians who were also the project directors. The families followed at the Developmental Pediatrics Clinic proved more

likely to be engaged and to participate in PPHE. All the families that participate in PPHE were known to Dr. Carugno or to Dr. Erickson. Parents were offered $20 for each encounter: training, interview and accompanying the physician to a community agency visit. All of the families agreed to participate even before the stipend was offered.

Each second and third year resident completed one visit to the home each year. These visits lasted around two hours each. Many of them were scheduled so that the physician arrived at the home, met with the main caregivers for one hour or so, and was there when the child arrived from school. If the resident had not met the child previously, this was an opportunity to see the child interact with the family at home, instead of meeting the family and child at the physician's office or during an emergency situation.

Since the residents saw that same family in the second and third year of their training, most families participated in PPHE for at least two years. This continuity allowed the resident to witness the growth and change that happened in the year between the visits. Some of the families had also expressed their appreciation that the residents saw their child across time. In one situation, after a resident had accompanied the family to the child's school year celebration for two consecutive years, the partner family called to ask if the resident could come to the child's graduation for the third year. This could not be arranged because the resident had completed her residency training the year before and was no longer at the hospital. Clearly, a number of the families were eager to continue their participation in PPHE and would request the assignment of a new resident after their initial resident partner completed his/her training.

Clinical Experiences

First year residents of both residency programs visit homes of children with disabilities accompanied by visiting nurses from St Mary's Hospital for Children. After the first year, the clinical experiences were different for the pediatric and the FM residents. Most clinical experiences for the pediatric residents were included in the developmental and behavioral pediatric/pediatric neurology rotations during the second and third year of their training. During the rotation the residents worked in both the Developmental and Behavioral Pediatric Clinic and the Pediatric Neurology Clinic for 4 to 6 half- day sessions. Other clinical experiences included a visit to the St. Mary's Children's Hospital inpatient rehab unit, where the residents examined children with severe developmental disabilities supervised by the pediatric neurologist, as well as observed children working with various therapists including OT, PT, speech and language therapists, feeding therapists, and psychologists. The residents also visited the NY Institute for Special Education, where they saw children with visual impairment and children with severe emotional problems. Other clinical experiences occurred during outpatient and community medicine rotations.

After PPHE began, FM residents asked for more exposure to pediatric patients. To accommodate their request, visits to the Howard Haber Preschool of AHRC (a special education preschool), United Cerebral Palsy of NY, the medical clinic of AHRC, and the developmental clinic of St. Barnabas Hospital (SBH) were added to the clinical experiences for the second and third year FM residents. Since PPHE began, adults with developmental disabilities who received medical care at SBH have been assigned to FM residents so that each doctor provides continuity of care for at least one adult who has a developmental disability during their training.

Lessons learned

While this may seem obvious given 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

services; 3) the attitude of medical and educational care providers toward individuals with disabilities and their families; and 4) the impact that having a disability has on the child, the parent and the 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 better remember the issues and prioritize them more realistically.

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. Other parents commented that they felt more confident in sharing information and requesting feedback from their child's physician because of this experience.

Best Practices

- Since home visits were a new experience for most residents, it proved helpful to have those who had completed their home visits speak about their experience with residents starting PPHE. Having the residents who had visited a home talk about how welcomed they felt and how comfortable it can be reassured other residents who might be concerned about their safety and their acceptance in the home. Some of the residents who participated in PPHE during the first grant year were videotaped as a way to introduce the PPHE curriculum to those in following years.

- Accompanying an experienced professional who modeled appropriate behavior during a home visit provided safety and structure to the resident's first exposure. Residents were given a sample of interview questions for the home visit as well as an outline for information to be gleaned from the agency visit. These steps also helped residents feel more comfortable in venturing out from the medical center.

- It proved 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. The process was revised to delay parent orientation until shortly before a home visit was made.

- Since a common language makes it easier for the parents to share their feelings and experiences, Spanish-speaking residents were matched with Spanish-speaking families whenever possible.

- Debriefing soon after the visit allowed 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 was better recall for recent experiences. It also avoided the problem of gathering residents from different rotations and different locations.

- Developing a flexible curriculum that fit into the existing residency program (rather than making it an add-on) made it easier to accommodate the PPHE components in the resident's busy schedule.

- Using a single rotation for most PPHE activities worked better than leaving the assignments open-ended. The community medicine and the behavioral and developmental rotations seem to offer the best flexibility for scheduling PPHE activities. The PPHE coordinator can easily schedule the activities for the residents in advance rather than expect the residents to arrange agency and home visits.

- When possible, PPHE components should be included in each year of training. This allows for: 1) more general exposure to individuals with developmental disabilities; 2) more repetition to aid

learning; 3) the differing perspectives of different levels of training to highlight different aspects of care of individuals with developmental disabilities; and 4) 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.

Sustainability

PPHE received institutional support from its inception. This support remained high during PPHE's three year demonstration at St. Barnabas Hospital. The residency program directors and chairpersons of the Pediatric and Family Medicine programs facilitated the integration of PPHE into their respective educational curriculums. It is useful that components of PPHE fulfill several requirements for training and competencies as required by the Residency Review Committee. For example, the PPHE personal reflections are important for requirements for self-assessment for the FM residency program and will easily remain incorporated. Likewise, learning to administer the Denver II Screening Test fulfills a competency in developmental screening required for the pediatric residents and will also remain easily incorporated.

The hospital administration has seen the value of integrating the PPHE educational curriculum into the competencies of its trainees as well. PPHE fits into cultural competency training that the hospital is required to provide to the staff. The inclusion of disabilities awareness and sensitivity expands the concept of cultural competence in ways that allow residents to go beyond traditional racial and ethnic definitions of cultural diversity.

Integrating the goals of PPHE with the residency requirements is vital to the integration and sustainability of the program. For this incorporation to remain practical, it is useful to have a designated rotation to complete the parent interview and the agency visit. At St. Barnabas Hospital, this was mostly accomplished during the developmental and behavioral pediatric rotation for the pediatric residents and during family medicine outpatient rotation for the FM residents. From this perspective, PPHE is integrated into the ongoing residency curricula.

Many community agencies have found the relationship with St. Barnabas Hospital mutually beneficial. It gives agencies access to medical resources for a population known to be medically underserved. Many agencies also welcome the opportunity to inform members of the medical community about the services they provide as a way of increasing their referral base. They are often also eager to educate physicians on what the physicians can do (such as writing/renewing orders promptly) to facilitate individuals' ability to get and utilize services. Through PPHE, St. Barnabas and the community agencies all increase their ability to provide care for children and adults with disabilities in the community and increase interaction with others in related medical and non-medical fields. As a consequence, most agencies have been receptive and agree to participate in PPHE, providing their staff's time "in kind." Other agencies welcome St. Barnabas lecturers or other educational opportunity in return for their providing training for the residents. Overall, the exchange of service will allow for the continued involvement of many community agencies. This network will support continuation of PPHE.

EVALUATION

Approach to Evaluating PPHE

DDPC's program staff included evaluation as an important element of their five-year Parent Partners in Health Education initiative. COGME was awarded a grant to provide technical assistance, sustainability planning, and overall evaluation for the projects, while each grantee had an obligation to cooperate in the evaluation process. The elements of the evaluation strategy were adopted from the evaluation process used with the original PPHE projects in Illinois.

The evaluation strategy included quantitative and qualitative data. The quantitative data consisted of a pretest, post test, lecture and case presentation evaluations, parent partner evaluations, and an end of the year resident's evaluation. The qualitative data consisted of Likert-scales that assessed attitudes and opinions on the pretest and post test, resident's reflections and feedback from the PPHE project directors. All grantees received Institutional Review Board approval for the evaluation.

Three limitations to the evaluation need to be noted. First, experience in the first year of the initiative indicated that most residency programs implementing PPHE did not have sufficient time to complete all components of the evaluation. The expectation for evaluation was reduced to the pretest and post test, which were supported by materials collected on the resident's reflections and interviews with the PPHE project directors. Even so, the ability of grantees to secure a 100 percent response to the pretest and post test was uneven.

Second, the pretest and post test underwent some changes over time. The COGME evaluation strategy was initiated after the PPHE projects commenced. The four Phase I grantees designed their own pretests and implemented them before COGME's pretest was available. The grantees agreed that a common pretest and post test would be preferred, but this change meant that the first pretests in July 2005 were not comparable to each other or to pretests that followed in subsequent years. A public law referenced in the COGME pretest and post tests changed, necessitating revisions to both the pretest and post test. Consequently, this chapter focuses on evaluation data for 2006-2007 and 2007-2008.

Third, the residents did not experience PPHE in exactly the same way. Pediatrics and family medicine residency program have different Residency Review Committee requirements. Pediatrics has a required developmental and behavioral rotation; family medicine generally does not, although the family medicine grantees made changes to their curricula to include new material. The other factor affecting the residents experience was the variation in program models. One pediatric residency program implemented PPHE with PGY1s; the two family medicine residencies focused on PGY2s; one pediatric residency program conducted the program over three years; and the third pediatric program involved PGY1 and PGY2 pediatric and internal medicine/pediatric residents. The elements of the PPHE curriculum were the same in all Phase I demonstrations, but each grantee customized the PPHE curriculum to fit its residency curriculum and community. While the variation in residency programs and the PPHE implementation model produced somewhat different experiences for the residents, it also illustrates how adaptable the PPHE curriculum is.

Quantitative Data

The pretest and post test contained questions of fact (i.e. questions with only one correct answer) and Likert-style questions that assessed both opinions and attitudes. The pretest and post test contained 18 questions of fact. The grantees were successful at getting 100 percent completion of the pretest but all were not able to achieve that response rate for the post test, since the post test was typically given in June

as the residency year ends. The following table presents pretest and post test scores from three sites. The number of participants per site ranged from 6 to 16.

Comparison of Pretest and Post Scores

Percentages based on correct responses to multiple choice questions

Site	2006-07 Pretest Scores	2006-07 Post Test Scores	2007-08 Pretest Scores	2007-08 Post Test Scores
St. Barnabas Pediatric Residents	52% PGY1	67% PGY3	62% PGY1	72% PGY3
St. Barnabas Family Medicine Residents	47% PGY1	85% PGY3	55% PGY1	50%PGY3
Winthrop Pediatric Residents PGY1	53%	48%[1]	44%	72%
St. Elizabeth Family Practice Residents PGY2	38%	47%	62%	66%

[1] Not all residents completed a post test.

Additional post test data was secured in June 2008 from residents who participated in PPHE in previous years at Winthrop. In 2009, Winthrop PGY2s answered 69 percent of the fact questions correctly. This group had a post test score of 48 percent correct the previous year. Winthrop's PGY3 residents correctly answered 74 percent of the fact questions. It appears that PPHE experiences (from a one year PPHE program) continue to be reinforced in subsequent residency years as seen in the even higher scores after completing the PPHE curriculum. Similarly, the PGY3 pediatric residents at St. Barnabas, having participated in PPHE for three years, scored higher in June 2008 than did the PGY3 residents who participated for two years.

It is important to recognize that many of the residents are foreign trained physicians. While they met all educational and language requirements for U.S. residency programs, there may be other differences that affect test scores. They would very likely be unfamiliar with community agencies, state and federal legislated services, and the accepted approach to caring for individuals with developmental disabilities.

Qualitative Data

Residents were asked to write reflections on their home visits as a pedagogic tool to reinforce learning and to put their experiences into perspective. When getting the resident to write open-ended reflections proved difficult, the project directors modified the expectation by asking them to respond to a template of questions, verbally note their reflections during one-to-one debriefings, or include their reflections in their case presentations.

Resident responses to their PPHE experiences have been similar across sites and across grant years. The following eight themes and resident quotes (in italics) are typical of the residents' experiences:

1. Parents bring valuable information to the physician; they are good observers and have better than ordinary insights regarding their children.

(The mother) *noticed that, at around three years old, B was just not like other children. She said that from the minute he came home from the hospital he could not be consoled; he just cried uncontrollably most of the time…* (The mother) *said she honestly thought that her son was different, although she did not really understand what it was about him that was so strange. She told her pediatrician many times that B just didn't seem like normal to her, that he wasn't talking, etc. She was told that she was just an overly protective, overly concerned mom, in part because of her personal problems.*

2. Caring for a family member with a disability requires a tremendous effort financially and emotionally, and often changes family dynamics.

I am in awe as to the resilience and persistence of this family in surviving whatever is thrown their way.

(The parents) *work on different shifts and on weekends,* (the parents) *are together. It is very difficult but* (the parents) *try to handle it as best they can.*

(The parents) *admit life is stressful; however, their goals for their children include helping them to be the best they can be, to keep them happy and to achieve this one step at a time.*

I learned that Mrs. C and her husband tend to argue more, that their relationship with each other has changed in the sense that they cannot share "married life" the way (they*) once* (did) *due to* (their child's) *autism. I learned that Mrs. C gets depressed a lot.*

3. Early discovery and notification are important to families. Patient-parent-physician communication and collaboration is essential, beginning with the initial medical tests. Parents need clear and full explanations.

Ms. D. offered a lot of information because she wanted to make sure that (the residents) *understood what parents of autistic kids go through and* (to avoid having) *other parents relive what she went through - not getting enough information to help* (her son) *and a psychologist* (who) *delivered the diagnosis without any explanation and support.*

When B was born, he had respiratory failure and he was transferred from the delivery room to ICU, and for several hours nobody knew what happened to him, Is he alive or not? The doctor who was on call said that the child's condition is very serious and he should be transferred to Syracuse. When (the mother) *signed the consent form, the doctor on-call said, Oh, if your last name is W, do you know your child most likely has Down Syndrome.* (The mother) *said, we could not understand what Down syndrome meant, but we understood something bad happened to our son and it was a shock for us.*

4. Parents are astute, self-educated, and pro-active in seeking out information and services for all aspects of their children's lives.

The parents understand that something wrong happened with their baby, but they did not know much about Down syndrome. She did not even know what to ask, and only after she read on the internet about Down Syndrome and after a genetic consultation, did she understand about G's diagnosis.

According to dad, he expressed a lot of concern that there is a lot of red tape when it comes to getting anything for the child. It has been like an uphill battle, and he has done all he can to make sure that the child gets everything.

(The parents) *have made personal efforts to educate themselves about the nature of their children's problems.*

What was striking to me was that (the mother) *was very focused on working with the resources available* (for) *her son, and actually pushing the professionals in Ds life to give him attention and a plan to identify goals that are reachable yet a constant stretch for him…knocked heads with one of D's teacher*…(over a goal that) *was not something she thought her son was unable to achieve; she thought*

this goal was too easily attainable…She is well aware of the resources that should be available to her son under the "Americans with Disabilities Act".

5. Caring for a child with disabilities is difficult for one person to handle. Parents do not always share responsibilities equally in caring for a child with a disability. Family and agency assistance is often needed.

(The family) *left Florida for upstate New York where they grew up and had family whose support they desperately needed. It turns out that the support came mainly from* (the wife's) *family and less from her father's side…Friends have thinned out with only the most dedicated ones remaining. They admit that life is stressful….*

(The mother) *revealed that she doesn't get that much respite. Her husband has been helping a bit more with the kids, but not to her satisfaction. She still does the majority of care giving for the children…When I asked about her support network, she was evasive, and I received the impression that she doesn't have many friends or many opportunities to socialize. She admits that often she feels as if she has lost touch with the outside world.*

6. Despite the difficulties, families strive for normalcy.

Yet when you meet both children, you see a stable home with two happy kids.

The favorite time, the best time for J is weekends when both parents and his brother and sister are at home, and they usually spend time outside and have fun. They like camping.

7. The primary care physician's role includes advocacy and referral.

(The parents) *never changed their pediatrician and R is almost 12 and* (they) *have only one primary care physician. But, he does not pay much attention to* (the child's) *development, social issues, and how R is doing in school.*

The general practitioner that she uses for her son's healthcare is, in her opinion, not up to date, and that this doctor has actually stated that he is not qualified in the areas T needs him most. However, (the mother) *cannot find a specialist for her son (in this area).*

She said that she has gone through what she calls the "doctor dance."

(Regarding an agency psychiatrist, the mother) *does not like her on either a personal or a professional level. She has found this doctor to be unresponsive and unavailable, that she prescribes medicine more by rote than on the individual strengths and weaknesses demonstrated by her son. She would really like to have access to a Pediatric psychiatrist, but has been unable to locate one in this area that accepts Medicaid insurance.*

(From my agency experience, I see the need to) *work toward coordinating the various services such children need, and be more apt to refer to early intervention. From what I've seen, it's much safer to err on the side of caution.*

8. PPHE curriculum components, e.g. home and agency visits, reflections and small group discussions, cause the resident to ask questions, confront their emotions and attitudes, and gain perspective.

Going to meet the mother of B and seeing the way she interacts with her child has been a very touching experience for me.

I have never had a personal encounter with a child with a disability this far in my life.

I think this (visit) *was very positive for me since it made me understand on a different level than when I see a patient in the clinic, the daily difficulties of life in a family with a child with a disability.*

As I waited for them to arrive at the hospital, I wondered how Mrs. D was going to get V to the hospital. What if the caretaker was not there (to help)?

(After we met the nurse practitioner for an evaluation, she asked for) *the same information from her history that needs to be told over and over.*

What will happen to D if her mother was not there? What will happen to her if there is no Mrs. D who advocates for her welfare?

To be around someone who just met you and to get the trust wholeheartedly humbled me.

I was rather apprehensive prior to meeting B for the first time …but (I knew that) *it would be an eye-opening experience, to participate in this project.*

I learned a lot from my (agency) *visit. Again, I hope to continue to learn about what to look for in children with/without learning disabilities so that the appropriate intervention can be made and made early enough to have some impact on the child's life and the families.*

I though one thing was interesting: t was not possible to tell that some of the children had autism as they appeared "normal" in the every sense of the word.

Meeting Mrs. G yesterday will be an experience that will stay with me through our career as a pediatrician. I have always found that learning about something on paper is never the same as having sat and talked with someone who lives it every day. I will always further investigate any concerns a parent has about their child's development, whether they are first time parents or not… The more resources we are exposed to now, during our training, the better for our patients later on.

Attitude Change

Both pediatric and family medicine residents experienced changes in opinions and attitudes about working with families and children with developmental disabilities during their involvement with PPHE. Post test results showed increased confidence in these areas:

- Feeling adequately trained to do screening
- Feeling comfortable with managing screening
- Familiarity with the home life of children with developmental disabilities
- Awareness of the difficulties facing many families with a child with developmental disabilities
- Familiarity with community resources and support services for children and families
- Feeling comfortable providing health care to children with developmental disabilities
- Feeling confident in their knowledge of developmental disabilities
- Awareness of laws concerning individuals with developmental disabilities

Both the pediatric and family medicine residents remained positive about the value of participating in PPHE for themselves and for other residents. They differed on what they saw as impediments to providing care. On the pretest, pediatric residents identified insufficient depth of knowledge as the number one issue and lack of experience as the second most important impediment. On the post test, lack of experience was identified as the number one impediment and time constraints as the number two concern. Family medicine residents identified the same number one issue (lack of experience) and number two issue (insufficient depth of knowledge) in both the pretest and post test, although there was a one-third decrease in the number of people seeing these issues as impediments.

Family Medicine Residents

Because the PPHE curriculum introduced new and/or more detailed information for family medicine residents, their opinions and attitudes about working with families and children with developmental disabilities is informative. On the post test: 69 percent felt adequately trained to do screening, compared to 62 percent who felt inadequately trained to do screening on the pretest; 75 percent reported feeling comfortable managing screening , compared to 15 percent who said they felt comfortable on the pretest; and 18 percent more agree that they should manage screening on the post than felt that way on the pretest.

Also on the post test: 46 percent fewer family medicine residents thought insufficient depth of knowledge and lack of experience were impediments to providing care, and 6 percent – 12 percent fewer family medicine residents thought difficulties coordinating care, difficulties referring to specialists or time constraints were problems. Opinions about the seriousness of language barriers as impediments to care were unchanged, with about a third seeing it as a problem and a third seeing it as not a problem.

Conclusions

Based on the three-year Phase I PPHE demonstrations described in this report, several observations can be made.

- The PPHE curriculum is flexible enough to be adopted in different residency programs and applied through different models (i.e., focus on one or multiple residency years, assignment of time for didactic lectures and agency and home visits, and recruitment processes for parents). PPHE didactic lectures and community medicine case presentations can be incorporated with other lectures at grand rounds or noon lectures, which are open to faculty and others interested in the topic.

- The first year's experience with the PPHE curriculum allowed the residency programs to refine their process for scheduling home and agency visits, recruiting parents, and arranging clinical experiences. This introductory year allowed both the PPHE directors and the residents to become comfortable with the curriculum and expectations for the program. The PPHE program operated better during the second year and even better in the third year.

- Leaving the hospital or other residency site for home and agency visits was not a problem. In most cases, the resident was accompanied by a faculty member, visiting nurse, or project coordinator who modeled both appropriate behavior and professional interviewing skills and whose presence increased the resident's comfort in this new situation.

- PPHE project directors have consistently pointed out that the PPHE curriculum meets RRC residency program requirements for continued accreditation. For example, for pediatric interpersonal communication skills, residency programs are asked to write a brief statement to describe one learning activity in which residents develop competence in communicating effectively with patients

and families across a broad range of socioeconomic and cultural backgrounds, and with physicians, other health professionals, and health related agencies. It would be appropriate to describe the PPHE home and agency visits as satisfying this requirement. An example for family medicine is the Family Oriented Comprehensive Care section that asks about teaching skills on chronic illness, behavioral counseling, family structure and dynamics, genetic counseling, and the role of the family in illness care. PPHE didactic lectures, home visits, group home visits, and clinical experience with children and adults would satisfy these requirements.

- Residents who participate in the PPHE curriculum gain confidence in their abilities to screen and care for individuals with developmental disabilities. This confidence will make them more comfortable as practitioners to accept new patients with developmental disabilities.

- Resident quotes illustrate that the home and agency visits have a strong impact. Many residents often commented on how the experience will affect their future clinical practices.

- The PPHE curriculum is supportive of the Medical Home model. It recognizes the primary care physician's role in coordinating care and services for individuals with developmental disabilities.

- The demonstration projects had no difficulty recruiting parent-partners. Parents are willing to share their stories with residents to help the residents learn from the positive and negative experiences the families have encountered as they sought help for their children.