

PARENT PARTNERS IN HEALTH EDUCATION



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

FINAL REPORT FOR 2006 - 2009 PROJECTS

July 2009

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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 2006 and 2009. Four teaching hospitals, listed below, implemented the PPHE curriculum in six medical residency programs during the second phase of this initiative. The New York State Council on Graduate Medical Education (COGME), in 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. The final report for the four Phase I projects was published in August 2008. This report summarizes the experience of the Phase II projects funded from 2006-2009. The dedication of all the PPHE grantees has been impressive. They have been innovative in their inclusion of PPHE into their residency curricula. The amount of training and experience required of medical residents is extensive. Yet, the PPHE curriculum is seen as enriching the residents' experience. DDPC's PPHE initiative 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 II. The chapters on individual grant sites describe unique aspects of each program. Each grantee describes her 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, lesson 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 their caregivers. 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. The New York initiative included three phases, each with four teaching hospitals funded for three years. DDPC made the awards via a competitive grant 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. The report on the Phase I projects, which operated from 2005 to 2008, was issued August, 2008.

This is the final report of the Phase II PPHE grants implemented between 2006 and 2009 by Maimonides Medical Center, Brooklyn, NY; New York Medical College, Valhalla, NY; Morgan Stanley Children's Hospital of New York Presbyterian, New York, NY; and SUNY-Upstate Medical Center and Center for Development, Behavior, and Genetics, Syracuse, 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 that present basic information, including an organizational session on PPHE, 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 about available community resources and that 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 measure 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 its focus on individuals with developmental disabilities and the inclusion of home and community agency visits as key components. The core curriculum centered on children, as successfully applied in four pediatric residency programs in Phase II. One of the Phase II programs, SUNY-Upstate, also used PPHE in a family medicine residency for two years and in a psychiatry residency program for one year.

Parent partners (i.e., parent volunteers who share their lives and experiences with the residents) become part of the residency teaching team. Residents, as well as faculty physicians, usually see children for routine office visits or during crises, and have little knowledge about the family's and child's daily life. It is eye-opening to see the home environment, meet others in the household, learn about and observe the care and professional services received by the child, and appreciate the stresses faced daily by the family. This knowledge adds to the physician's ability to provide family-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. SUNY-Upstate piloted the approach of initiating a relationship between residents and the families of NICU babies with developmental disabilities, who would then be followed through the hospital's continuity clinic. Morgan Stanley Children's Hospital (MSCHONY) maintained continuous relationships with families as departing third year pediatric residents assigned their children who had disabilities to first year residents to work with for the next three years.

The philosophic basis of 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. The residents see speech pathologists, physical therapists, and others applying their skills to support the child's development and abilities. This is a good opportunity to gain an appreciation of how team work benefits the patient and family. Often, the agency visits involved 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. Maimonides chose to implement the curriculum in one year only as part of their developmental and behavioral rotation. The 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 nine pediatric residents and 11 family medicine residents completed their program's PPHE model. Another 218 residents, who were at different stages of the residency process when the PPHE program began, completed most of the curriculum. For example, residents in their third year of residency when the PPHE program began would have participated in some but not all of the PPHE activities offered for first or second year residents.

Number of Primary Care Residents Trained 2005-2008

Maimonides Medical Center Pediatric Residents 78

Morgan Stanley Children's Hospital of New York Presbyterian (MSCHONY) Pediatric Residents: 20 completed the full 3 year program.
Another 80 completed 1 or 2 years.*

New York Medical College Pediatric Residents: 30 completed the full 2 years
Another 49 completed 1 year

SUNY-Upstate Medical University Pediatric Residents: 11 completed the 2 year PL1 & PL3 program.
Another 52 residents completed either the PL1 or PL3 program*
Family Medicine Residents: 11 completed the 2 year program.
Another 26 completed either the PL2 or PL3 year.*
Psychiatry Residents: 11 completed 1 year

*Programs done over multiple years repeated the lectures, made home and agency visits, did community medicine presentations, and had clinical experiences each year, although with different emphasis.

Didactic Lectures

All grantees were required to provide four basic PPHE curriculum lectures. The project officers with their PPHE Planning Groups 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 on the administration and interpretation of the Denver II assessment tool but often covered other assessment tools, including the Modified Checklist for Autism in Toddlers (M-CHAT) and parent evaluation tools (e.g., Parents' Evaluation of Developmental Status (PEDS) and Ages and Stages).

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 II had to be flexible in scheduling the didactic lectures. All experienced difficulty scheduling lectures at times when most residents, particularly the third year residents, could be present. Solutions included: Recording 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 (e.g., noon conference or grand rounds) for PPHE lectures or case presentations.

Maimonides offered the didactic lectures during the developmental and behavioral rotation and utilized their OSCE (Objective Structured Clinical Examination) on communications to reinforce Doctor-Patient-Family Communication skills. MSCHONY involved all three residency years in small group lectures presented by an itinerant instructor or precepting attendings in the continuity clinic, which were then placed on the community pediatric website. They also utilized an existing participatory workshop on cultural competence to address physician-patient-family communications.

One grantee, New York Medical College, implemented a faculty development session for precepting attendings to make sure that they were informed on the PPHE topics being presented to the residents.

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. Most grantees scheduled two or three case presentations a year. Maimonides organized quarterly medicine case presentations and discussions at standing departmental meeting/professorial rounds. SUNY-Upstate had their first year residents complete a case presentation during the Developmental Pediatrics Seminar at the end of their developmental pediatrics rotation. Their third year pediatric residents and psychiatry residents made a case presentation during the Friday outpatient pediatrics conference, at an outpatient pediatrics non-conference, or at a grand rounds warm-up talk. MSCHONY tapped two PGY3 residents to present their partner family experience at Chief of Service rounds.

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. The following table records how small group discussions and resident reflections were handled by the Phase II grantees.

Small Group Discussion and Resident Reflections

Program	Small Group Discussions	Resident Reflections
Maimonides	Held at the end of Developmental & Behavioral Pediatrics month (2-3 residents plus faculty)	Keep a personal journal with impressions of home, agency visits, other PPHE experiences
New York Medical College	Informal discussions held over lunch to discuss resident reflections on the PPHE experience and their family meetings	Recorded thoughts on e-mail

Program	Small Group Discussions	Resident Reflections
Stanley Morgan Children's Hospital	Focus on 2 nd or 3 rd year residents' experiences during continuity clinic conferences. One session for each residency year.	2 nd and 3 rd year residents collected at the end of each Outpatient and Community Pediatrics block
SUNY-Upstate	<p>First year pediatric residents discussed communication skills during structured debriefing sessions with psychiatry residents at the end of their developmental pediatrics rotation.</p> <p>Third year pediatric residents completed a case presentation during the Friday Outpatient Pediatrics noon conference.</p> <p>Psychiatry residents discussed system navigation skills during structured debriefing sessions with PL1 and PL3 residents at the end of their developmental pediatrics rotation</p>	Residents were provided a journal template to record home visit and agency visit experience. The journal was used as framework/outline for Community Medicine Case Presentation.

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.

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.

MAIMONIDES MEDICAL CENTER

Project Director: Lisa Altshuler, PhD. Co-Director, Developmental and Behavioral Pediatrics

Project Assistant: Ibsen Vargas

Approach to PPHE Curriculum

The Maimonides Medical Center (MMC) PPHE Curriculum was implemented during the mandatory Developmental and Behavioral Pediatrics Rotation. This was chosen because the rotation is a defined period when dedicated resident time could be devoted to the curriculum. It was felt that such intensive experiences over the course of a month would enhance learning, as residents would be immersed in this experience. And, based on the challenges of the PPHE curriculum (including multiple lectures, small group discussion and family and agency visits) and past experiences with other curricula involving outside agencies, scheduling and ensuring resident follow through would be problematic if the project was spread over a longer time period. Finally, since the Developmental and Behavioral Pediatrics rotation occurs within the first year of residency, residents would have an opportunity to utilize the knowledge gained from the PPHE as they continued seeing patients, particularly in their continuity clinics, during the remaining years of their training.



Getting Ready to Implement PPHE

Prior to implementing PPHE, Maimonides Pediatrics was committed to family centered care and working with community resources to provide better care. Families were an integral part of the health care team, both on an individual case level as well as in the development of policies and facilities (e.g. an active Family Advisory Board). Similarly, residency training focused on developing the knowledge, skills and attitudes necessary for providing culturally competent, comprehensive care to children and their families, particularly those with chronic health issues. However, there were gaps in training related to developmental disabilities. Expectations for the PPHE curriculum were high. It would provide opportunities to strengthen the residents' ability to learn about early identification and referral for children with developmental disabilities; increase their knowledge of community resources for children and their families; identify and promote patients' and families' strengths and resilience; and learn to coordinate with families and community resources to enhance the care for children with disabilities.

Planning for the project was done by a core group that included a medical educator, psychologist, developmental pediatrician, and primary care pediatrician, who would develop and implement the curriculum. This group reported to and got input from the Residency Training Director and the Departmental Education Committee as well as the Department Chair. This group adapted the original PPHE curriculum materials and approaches to make them relevant for an urban, multicultural setting with culture-specific needs and sensitivities. The PPHE program was introduced to PL-1 residents during their initial orientation to the Department and to their residency program. Incoming residents were open to the program, seeing this as an opportunity to learn from and connect with parents. They accepted this as an expected part of their residency program.

The specifics of the Maimonides program include:

1. Didactic Lectures:

- a) The PPHE program was introduced to first year residents at an initial lecture during their orientation week. This lecture also presented the concepts of family centered care and the medical home. Presenting this as residents are beginning to learn about their residency program highlights the importance of these topics.
 - b) One hour per week during the Developmental and Behavioral Pediatrics month is devoted to a seminar series. Lectures on screening and assessment of developmental disabilities, and legal aspects and accessing services for children with disabilities are provided. Examples from patients seen at the Developmental Center and from agency visits are utilized to highlight salient points during the lecture.
 - c) **Physician-Patient Communication:** Rather than using a lecture format to address this topic, a more active, experiential learning approach was used to enhance skill-development in addition to gaining knowledge. All PL-1 residents have a one day workshop devoted to communication with children and families. Beginning with a two hour workshop, residents discuss their experiences communicating with people from different backgrounds and identify communication challenges. Then a model for enhancing communication is presented and discussed. Finally, residents have an opportunity to rotate through five stations where they can practice specific communication tasks with Standardized Patients (trained actors) and received individualized feedback from the actors and faculty observers. These scenarios have included tasks such as making a referral for a further evaluation for an ADHD child, explaining a medical procedure to a young child, talking about a medical mistake, communicating over the telephone about an issue, and exploring the reasons for a child with school-related difficulties. Finally the group reconvenes and discusses their experiences and the lessons learned.
2. **Parent Partner Interviews:** Two parent interviews occurred. The first was at the hospital, where residents were introduced to parent partners and learned of the specifics of the child and family's situation. They then made a visit to the family's home, where they talked further with the parents and met the child. Visits were scheduled at a time when home-based services were planned, so the resident also had an opportunity to observe a therapy session or other services. One objective was to shift the power relationship that can occur between physicians and parents by having the residents step out of their professional caregiver role and see the parents solely as faculty, not also as a parent of a patient.
 3. **Community Agency Interviews:** The Guild for Exceptional Children (a preschool program) and the Challenge Early Intervention Program were the main sites for the community agency interviews. Residents visited both sites, learning about the types of services offered and identifying ways to enhance communication between families, agencies and health care providers. They also learned about access and funding issues.
 4. **Clinical Experiences:** During the Developmental and Behavioral Pediatrics Rotation, residents spend the majority of time at the MMC Developmental Center, where they are part of an interdisciplinary evaluation team that includes psychologists, speech and language therapists, audiologists and social workers. They also spend one day in a Physical Medicine and Rehabilitation Clinic, where they have an opportunity to see patients along with physiatrists, physical, occupational and speech therapists.
 5. **Community Medicine Case Presentation:** Initially, an attempt was made to have these case presentations at a specially convened conference time at quarterly intervals. However, this proved logistically difficult. The conference was then scheduled during a regularly scheduled teaching conference. In addition to ensuring more participation from the residents who experienced PPHE, it also included all 76 residents across the three years of training as well as faculty members, further strengthening learning. PPHE residents selected a case to present, and parents and representatives from the community agencies were invited.

6. Small Group Discussions: At the end of the rotation, the two residents on the rotation met with Drs. Altshuler & Chan (Co-Directors of Developmental & Behavioral Pediatrics) to share experiences and reactions to their visits with parents and community agencies. They shared their journals that chronicled their parent and agency visits. The emphasis was on tying the resulting knowledge and insights to reflections about their approach to the patients they work with either in Continuity Clinic or other settings.

Challenges

1. Scheduling Agency and Parent Visits. Finding time to fit all the activities in during the month was the biggest challenge. Initially, residents had responsibility for setting up agency and parent visits, but it was difficult for them to complete all the expected visits during the month. Residents took a while to contact families, and then lost more time due to on-call schedules, other clinical responsibilities and rescheduling visits due to family/agency needs. The process was revised to involve a coordinator to schedule the visits prior to the rotation month. Then, when the resident began the rotation, the schedule was already in place, allowing for better utilization of the limited time during the month.
2. Parent Recruitment and Training. MMC's original approach recognized the importance of helping potential parent partners understand the goals of the project and how to communicate in ways helpful for the trainees. This took more time and collaboration than expected. Moreover, determining an appropriate time for families to participate was important in ensuring a positive outcome for all involved. For example, some parents, who had recently received a diagnosis with their child or who were still working to cope with a particular situation, had difficulty presenting a balanced view of their experiences.

Community Agencies

MCC's Community Agency Partner Advisory Group met twice a year to review the implementation of the project and identify any difficulties or areas for improvement. Two of the four partner agencies became the main partners, primarily because of proximity. One, a preschool program, is located across the street from the Residency Primary Care site and residents made site visits there prior to the grant to observe the classrooms as part of their learning experience. The second, an early intervention program, was a referral site for some of the graduates from the Neonatal Intensive Care Unit, but did not have a strong relationship with the hospital. Relationships with both sites were strengthened as a result of PPHE. At the Advisory Group meetings, agency staff and hospital primary care pediatricians got to know each other better and were able to discuss ongoing clinical needs and issues about medical needs, therapeutic and educational options. The meetings (and the project itself) had the benefit of providing faculty development and has resulted in enhanced care for children. In fact, this has been one of the unexpected highlights of the program.

Parents Recruitment

Parents are recruited from the Developmental Center as well as community agencies. MCC's coordinator met with potential parent partners to explain the program and to learn about the child and the family. Stipends were provided initially, although because of funding issues MCC is now recruiting parent partners without offering stipends. Many of the parents participated for more than one year, and they reported a sense of purpose and satisfaction from their experiences as Parent Partners. There were two interviews per resident: an initial visit at the hospital and a home visit. The initial visit usually lasted 1-1½ hours, while the home visit was about two hours.

Clinical Experiences

Residents had almost all of their clinical experiences at the hospital. These included seeing patients at the Developmental Center with a precepting Developmental Pediatrician, and attending at least one clinic with a psychiatrist during their Developmental rotation. They also routinely screened for developmental and behavioral issues during their continuity clinics, with supervision and precepting by Primary Care Pediatricians. (This clinical experience extends across their entire residency, past their experience with PPHE.) They have additional opportunities to work with children who have developmental/behavioral issues during pediatric neurology and genetics rotations as well as other electives. Residents also take part in an “arena” evaluation during their visit to the Early Intervention site. This is an interdisciplinary evaluation where professionals see the patient and family at the same time (either being in the same room or from behind a one-way mirror).

Lessons learned

An essential part of the success of PPHE for Maimonides was having the curriculum implemented during the Developmental and Behavioral rotation, with clearly identified people assuming responsibility for ensuring that residents completed the program. Additionally, having a clear structure in place, with a coordinator setting up visits prior to the resident’s rotation month, was essential for ensuring that the program worked as planned.

Sustainability

The Pediatrics Department, including the Chair of Pediatrics and the Residency Training Director, strongly supports PPHE. Parts of the PPHE are now fully integrated into the Maimonides Pediatrics residency training program and are running smoothly. The lectures, clinical experiences and agency visits can be sustained without additional support. However, the family visits, which is one of the most important parts of the curriculum and the one that most strongly influences the residents’ attitudes, presents more of a challenge. Without funding to support a program coordinator, and with increased demands on faculty for productivity in this era of budget cuts, it will be difficult to recruit and train Parent Partners and schedule the visits for 25 residents each year. We have sought additional funding from Foundation grants but have been unsuccessful to date. PPHE has been a valuable and unique educational experience for the residents, faculty, parents, and outside agencies involved in its implementation. Existing staff is assuming the responsibility for administering the parent visits while we continue to search for additional funding for a project coordinator. MMC is motivated to continue PPHE as an essential part of the training for pediatricians.

MORGAN STANLEY CHILDREN'S HOSPITAL OF NEW YORK PRESBYTERIAN

Project Director: Heidi Beutler, MD

Project Coordinator: Martha Bolivar

Approach to the PPHE Curriculum

The PPHE program began at Morgan Stanley Children's Hospital of New York Presbyterian Medical Center (MSCHONY) in July 2006. It was designed to engage first, second, and third year pediatric residents simultaneously and to blend with other residency program requirements.

Each MSCHONY resident's primary care experience takes place at one of four community-based clinics operated by New York Presbyterian Hospital. Over three years, the resident follows his/her own panel of patients, some of whom have developmental disabilities. The basic step for integrating PPHE into the existing curriculum involved having each resident, early in the second residency year, identify a panel patient who has a developmental disability as a partner for home and community agency visits. This partnership continued until the end of residency.

Clinic preceptors, who are all Primary Care Pediatricians, supervise the residents in the care of their clinic patients and presented two the PPHE didactic lectures.

Key curriculum elements by residency year:

First year residents: Attend all four PPHE didactic lectures and community medicine case presentations.

Second year residents: Attend PPHE didactic lectures and community medicine case presentations. Make two home visits with partner family.

Third year residents: Attend PPHE didactic lectures. Present two Community Medicine Case Presentations at Chief of Service Rounds about a PPHE child and family. Make one community agency visit with partner family; and participate in small group discussions in continuity clinic.



Getting Ready to Implement PPHE

An early decision to interweave PPHE with other programs allowed MSCHONY to greatly enhance the experience of residents by including home visits and increasing their training specifically with children who have developmental disabilities. Residency program directors were receptive to integrating PPHE into the existing curriculum, which included an entire month of Developmental Pediatrics in the second year and a one month block each year in Ambulatory Pediatrics. Key to incorporating PPHE was the coordinator for the Community Pediatrics program. The coordinator was able to use and modify residents' ambulatory block templates and was already adept at scheduling faculty and parents for home visits.

The MSCHONY residency program already had an established Community Pediatrics curriculum, which included three faculty members who made home visits with first and second year residents. With the

addition of the fourth faculty member (PPHE Project Director), the second year residents added home visits with PPHE partner families.

The community pediatric visits were facilitated by Project DOCC (Delivery of Chronic Care) parents, who were also asked to take part in PPHE. Prior to 2006, Project DOCC parents had been conducting home visits and parent interviews with all third year residents. These visits all took place with Project DOCC families. For PPHE, Project DOCC parents acted as guides to accompany residents on home visits. These parents added their personal experiences with their own children with chronic conditions to what the residents saw and experienced.

A Developmental Pediatrician supplied the didactic presentations on developmental screening. An experienced itinerant teacher of the Denver II, this professional worked with small groups of residents assigned to each continuity clinic group. She also gave presentations on speech/language development, autism, and intellectual disabilities.

Another existing program that was utilized for PPHE was the yearly cultural competency training for first and second year residents. Doctor-patient communication is a focus for this training, in which a small group of residents meets for an afternoon with faculty members.

Challenges

Identifying children with developmental disabilities from continuity clinic panels. The goal was for residents to identify a PPHE partner child who had a developmental disability no later than the beginning of the second residency year. Some residents were not able to do this. Attending physicians in the clinics were made aware of the importance of helping residents gain experience with children with disabilities and aided the identification of children who could be matched with residents. The process of identifying a child who had a developmental disability was refined to have departing third year residents assign their children with developmental disabilities to incoming first year residents as potential PPHE partners.

Scheduling home visits. Some home visits fell through because the resident did not contact the family in time, the patient was hospitalized, or the family cancelled at the last minute. This problem was addressed by having the residency program coordinator assign specific times for home visits and by reminding the residents early to contact the family to set an appointment.

Scheduling community agency visits. Community agency visits sometimes did not occur because the scheduling was left to the resident who has to juggle multiple responsibilities. Early reminders to the residents helped, as did the flexibility to choose different agencies and times.

Evaluations. Completing program evaluations was difficult for a variety of reasons. The residents were rarely in one place at the same time and evaluations added more paperwork. It would have helped to have web-based pretest and post tests. Other residency programs interested in implementing PPHE may find it helpful to designate an individual, perhaps a faculty preceptor at the clinic, to be responsible for collecting evaluations.

Community Agencies

Because parent recruitment was done directly by the residents, there was no central community agency involved with PPHE. Rather, each resident became familiar with the agencies involved with the partner family and child. Residents had regular visits, during their Developmental Pediatrics block, to a number of schools in the New York City area attended by children who have developmental disabilities. They

also visit the Elizabeth Seton Hospital and Rehabilitation Center in their third year. Early Intervention agencies and therapists were also visited.

Parent Recruitment

Residents were given guidelines about choosing a patient/family for the partnership. They were given a brochure (available in English and Spanish) describing the program to potential parents. The recruitment was usually done at the beginning of the month when the first home visit was scheduled.

Clinical Experiences

Direct care of the resident's own patient over one to three years in clinic provided perhaps the most important clinical experience. Home and community agency visits gave the resident an understanding of how the child's condition affected the family and how the family's circumstances affected the child. This kind of insight is invaluable in providing quality care for children. Of course, residents also gained clinical experiences daily in the care of children who have developmentally disabilities, who are often medically fragile and who make up a large percentage of patients admitted to the hospital.

The PPHE residents developed expertise in detecting developmental delays in young children, since the majority of their clinic patients are infants and toddlers, whom they see frequently in well baby visits. Under the guidance of their preceptors, the residents gained the ability to diagnose problems and refer to Early Intervention when appropriate.

Best Practices

- The addition of PPHE home visits to existing Community Pediatric home visits strengthened the residents' awareness of the importance of parents and families. The residents gained insights on the impact of disability on transportation, scheduling appointments, juggling the needs of other family members, and coordinating care, among many other concerns.
- The presence of a Developmental Pediatrician facilitated implementation of PPHE in the community based clinics. The Developmental Pediatrician provided lectures, small group discussions, and one-to-one training that augmented the residents' experiences in the one month Developmental Pediatrics block.
- MSCHONY had experience working with parents and families through Project DOCC. Utilizing Project DOCC guides and volunteer families expanded the residents' experience. The working relationship provided organizational support for arranging visits and debriefings.
- Blending PPHE activities with other elements of the MSCHONY residency program aided its acceptance by involving other faculty who could reinforce the value of PPHE. Sharing resources, e.g., the cultural competence workshop on communications benefited the residents by successfully satisfying two requirements in a single event.
- Conducting PPHE over all three residency years emphasizes the importance of its lessons. Multiple home visits, attendance at multiple community medicine case presentations, and long term involvement with a family reinforce the value of a family-centered approach.

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

Sustainability

July 2009 at MSCHONY will see a major shift in residency training, due to a push for the residents to do research. The Community Pediatrics block in the second year is being eliminated and replaced with elective time meant for research. The residents have consistently praised the home visit experiences, but the second year home visit conducted by the Project DOCC parent will be eliminated due to time constraints. The second year residents will continue to make home visits with a faculty member.

Didactic lectures will be retained in a consolidated format. MSCHONY's Developmental Pediatrician will continue to train residents in small groups and one-to-one during clinic conference times, addressing assessments, and accessing services for children with developmental disabilities.

NEW YORK MEDICAL COLLEGE

Project Director: Karen Edwards, MD, MPH **Pediatric Residency Director:** Theresa Hetzler, MD

Approach to PPHE Curriculum

The main component of the New York Medical College (NYMC) PPHE Program was modeled on existing student/trainee family mentoring home and community visiting programs that have involved medical students and LEND (Leadership Education in Neurodevelopmental and related Disabilities Training Program) trainees for over ten years in a well-developed and time-tested curriculum on family partnerships and family-centered care. This component initially involved both PGY-2's and PGY-3's making one home visit and one community visit each but later was modified to involve just PGY-2's based on input from trainees, faculty, and families. PGY-3's then switched to a family-interviewing experience that used the same structure and guidelines but was accomplished by working with a family they followed in their own continuity clinic or with whom they had developed a relationship while the child was hospitalized.

Residents provided written feedback on their visits to the family coordinator and summarized their visits in writing before the de-briefing session. Visits and interviews were debriefed during an annual session led by the pediatric program director and attended by other PPHE staff and faculty. PGY-2's had additional related clinical experience in a developmental and behavioral pediatrics clinical practice. Residents at all three levels participated in case discussion (at the debriefing), in noon conferences and grand rounds where the key conference topics were covered, and in additional conference times. The community visit element of the PGY-2 experience took place by accompanying the family to a community activity, following the model that successfully used for the LEND program.

The conference topics were implemented into the noon conference schedule, into the continuity clinic talk schedule, and into Grand Rounds. For the first session offered, a well-known developmental-behavioral pediatrician from another LEND Program in New York State was invited to give grand rounds on *Developmental Screens & Surveillance: The Price of Security* and to follow it up with a case-based discussion with pediatric residents and community-based general pediatricians on the approach to the child who presents with developmental delays. This Grand Rounds also served as a "kick off" for the PPHE Program at NYMC. Other well-received sessions have included: a panel of parents and representatives of community-based organizations providing an introduction to community resources for children with disabilities and their families; trainings on developmental screening tools, including issues related to cultural competency; and a visual guide to signs of autism in young children.

Getting Ready to Implement PPHE

A plan was developed to recruit families for the PPHE program using methods and networks that have been quite successful in the past. The program had the strong support of the medical school, the residency program, and the GME office of the medical school. To raise awareness of the program in the college community, information sessions were presented to department chairs and members of the Graduate Medical Education Committee of the medical school. An article about PPHE was published in the on-line and print versions of the monthly medical school newspaper.

A resident was a member of the planning committee. Based on past experience in introducing new elements into the residency program, it was decided to introduce the PPHE curriculum and experiences using a presentation at joint annual group meetings of PGY-1's and PGY-2's to assure that a uniform message was given and that all had an opportunity to ask questions and receive satisfactory answers. The

presentation included sessions with program leadership (including family members) and past trainees from other programs who had participated in a family mentoring experience.

Challenges

Resident Involvement. Resident buy-in to this experience and self-assessed level of need for this experience varied over the course of the project, with the most recent group of PGY-2's being most enthusiastic in their appraisal that they indeed learned something from the family mentoring experience that they could not have learned anywhere else. The immediate collection of feedback from residents and families after the visits allowed for active oversight of the experience. This, combined with resident feedback at meetings and at year's end, allowed us to customize the experience to improve the "fit."

Scheduling and Collecting Feedback. The most significant challenges were 1) coordinating scheduling between families and residents and 2) collecting feedback from families and residents. These were addressed by having program staff handle these two functions and by creating a system whereby PGY-2's made visits only during their defined developmental behavioral pediatrics month-long rotation. It was the administrative coordinator's role to obtain open timeslots on the resident's schedule for PPHE home visits and to work with families to find dates that worked for them. The family coordinator's role was to communicate with the family and the resident before the visit (for preparation) and after the visit (to obtain feedback), and to summarize the feedback for the director and co-director.



Community Agencies

Westchester Institute for Human Development (WIHD), one of the lead partners in the project, is at once an affiliate of New York Medical College and an independent private not-for-profit community-based organization. WIHD has extensive community partnerships and networks from which it is able to draw support for the three major family mentoring programs it runs for trainees and students.

The NYMC Pediatric Residency Program at Maria Fareri Children's Hospital continues to have residents take part in activities in area schools. During the Developmental-Behavioral rotation, residents visit a suburban elementary school and attend a Committee for Special Education meeting. In the final year of the PPHE, residents began visiting the Westchester Center of Educational & Emotional Development, a multidisciplinary center providing evaluations and therapies for young children.

Parent Recruitment

WIHD has a long history of pairing students and trainees with families of children with disabilities as part of the Family Mentoring experience for LEND trainees and medical students. WIHD's large staff of service coordinators are mostly themselves parents of children with disabilities and other special health care needs. Many of them serve as "family faculty" for home visits. They are also able to offer suggestions for additional families to recruit from among the families with whom they work.

WIHD has never offered a stipend to parents who serve as family faculty for the home visiting program. Many families who participate in the three family mentoring/ home visiting programs through WIHD have volunteered in this capacity for many years.

During the PPHE project period, 64 residents made family and community visits. About one quarter of the residents (mostly during the first project year) made two visits each, but in subsequent years, only one visit per resident was made to the home and one was made to the community.

Clinical Experiences

Clinical experiences occurred both in the developmental –behavioral pediatrics clinic and practice and in the continuity clinics.

Lessons Learned and Best Practices

- It was important to meet with all PGY-1's as a group just before the transition into PGY-2 year, in order to describe the PPHE experience and set out expectations and answer questions.
- It worked much better to have PPHE staff arrange the home visits with residents and families, based on information from the residency program coordinator concerning the schedule for the Developmental-Behavioral Pediatrics rotation, than to have the residents make the preliminary contact with families themselves.
- Systematic collection of feedback from residents and families immediately after the visits allowed for immediate “course corrections” and for longer term aggregation of feedback to inform systematic program changes.
- It worked well to have the home visiting and community visiting elements of PPHE built in to a standing month-long developmental-behavioral rotation.

Sustainability

The residency program would like to maintain certain elements of the PPHE experience which add unique value to the program and which help them to fulfill aspect of “Community Experiences” set out by the ACGME. Discussions are underway to possibly continue the main elements of the PPHE experience, specifically one home visit and one community visit for each PGY-2 and selected noon conferences (on developmental screening and on community resources for families of children with special health care needs).

Feedback from Residents

Perhaps the best way to describe the impact of the PPHE experience is to include some direct quotations from PGY-2 residents who participated in PPHE home visits during the past six months.

- *I learned so much about autism and the school visit showed me how if present, resources and staffing can make a world of difference to give children the individualized time they need. ...I think that everybody should be allowed to have a school visit for their community visit. It was great to see Emily in her actual learning environment and see how she interacts with others. It was also good to see other students in her class as a comparison. This experience was so worthwhile.*
- *I definitely feel that the visit was worthwhile. It will help make us better pediatricians; it will make us more sensitive toward the issues concerning developmentally challenged children. I've learned a lot about useful community, school, and professional resources for these children and about the hardships and prejudices that these families often face.*

- *I thought the visit was very helpful. It was nice to see how patients act in their own environment when they are not sick in the hospital. I got to see pictures from when she was smaller and throughout the years. I would not structure it differently, I liked to see her in her home environment.*
- *I definitely felt it was worthwhile. It was great to see the family interaction in their own environment. Also, Mrs. C. was a wealth of information regarding the different services D. received throughout her life, and also different opportunities available to families and people with Down syndrome! The C. family are pro's at these types of interactions. They have been really great advocates for D. and they have been part of SO many different opportunities that they have SO much to share with us residents, I can't think of how this visit could have been improved.*

SUNY UPSTATE MEDICAL UNIVERSITY CENTER FOR DEVELOPMENT, BEHAVIOR AND GENETICS

Project Director: Nienke P. Dosa MD, MPH

Home Visit Facilitators: Susan Delaney NP, Julian Nedell

Administrative Assistant: Regina McConnell

Approach to PPHE Curriculum

The PPHE curriculum was incorporated into the training of the Pediatric (PEDS), Family Medicine (FM), and Psychiatry (PSYCH) residency programs of SUNY Upstate Medical University (SUNY Upstate). The program was launched with first and third year PEDS residents and second and third year FM residents during the first two years (2006-2008). In the final year (2008-2009), the PPHE curriculum was introduced to third year PSYCH residents as well. A core feature of SUNY Upstate's PPHE program throughout the three years was cross-disciplinary clinical training in developmental pediatrics at the Center for Development, Behavior, and Genetics. FM, PEDS, and PSYCH residents saw patients together, did joint home visits, and shared presentations about their PPHE experience at interdisciplinary seminars with faculty from the Center for Development, Behavior, and Genetics.

During the first year of PPHE, the four core lectures were created, archived on video, and placed on the residency programs' blackboard sites for reference and later viewing. The developmental screening lecture was redundant with another lecture already included in the PEDS lecture series, whereas this was new material for the FM residents. The lecture seminars were presented separately to PEDS and FM residents, due to scheduling constraints. This worked well, since the focus for PEDS residents was slightly different than for FM residents. Generally speaking, lectures for PEDS residents emphasized advocacy, whereas lectures for the FM residents focused on diagnosis and medical management.



The *PEDS interns* did the home and agency visits and their seminar presentation during their developmental pediatrics rotation at the Center for Development, Behavior, and Genetics. They were accompanied to home visits by a home visit facilitator, who was an experienced nurse practitioner with expertise in home care of children who are medically fragile. This served several purposes: 1) the resident did not need to arrange the home visit; 2) transportation was provided; 3) the nurse practitioner modeled appropriate in-home professional behavior and sensitive interviewing skills. Residents received an interview packet prior to the visit. This included an overview of the PPHE goals and objectives, a 2-page interview template for later reference in the seminar discussions, and a home visit "etiquette tip-sheet." Residents were encouraged to fill out the interview template on the ride home from the home visit. The ride home also frequently served as a "debriefing session" with the facilitator. Parent partners were readily identified from the patient panel at the Center for Development, Behavior, and Genetics. The agency visits occurred at one of twelve community partner sites. This, too, was pre-arranged for the resident, and transportation provided. Small group discussions and PPHE seminars were easily integrated into the PEDS developmental pediatrics rotation. The entire PPHE curriculum was compressed into the 4-week developmental pediatrics rotation. This made for a cohesive and relevant experience for the PEDS interns. From the outset, the PPHE curriculum was a resounding success for this group of residents.

It was more challenging to integrate the PPHE curriculum for *third year PEDS residents*. This was primarily due to scheduling constraints. The home and agency visits and seminar discussions were spread out over the entire third year, whenever residents were assigned to an outpatient pediatrics rotation. Residents were initially asked to identify families from their patient panel. This met with limited success, as residents either could not identify a family or were unable to arrange the home visit. A nurse case manager who worked on-site at the outpatient clinic eventually joined the PPHE program in order to identify families and schedule home visits. As with the PEDS interns, a home visit facilitator accompanied residents to the home visits and provided transportation. The agency visit for third year PEDS residents was scheduled on set days at the same elementary school during all three years of the PPHE. This arrangement worked very well primarily because the school nurse and one of the special education teachers at this school were committed to PPHE goals of educating residents about cross system collaboration. A strong link and effective communication channels developed between the school nurse and the outpatient clinic as a direct result of the PPHE program. An excellent working relationship evolved between the school nurse and the nurse manager at the University Pediatric and Adolescent Center and residents and faculty members from the University Pediatric and Adolescent Center frequently participated in IEP meetings for children at the school.

Second and third year family medicine residents participated in the PPHE program for two years. However the St. Joseph's family medicine residency program elected to discontinue participation in year three. Integration of the PPHE curriculum was problematic from the outset, primarily due to scheduling constraints. Other factors included a) off-site rotations at other hospitals, b) difficulties with identifying eligible families from the family medicine outpatient clinic panel and c) the fact that residents were charged with arranging their own home visits. Interestingly, the family medicine residency program already had in place a home visit requirement. Although it was initially believed that this would facilitate integration of the PPHE curriculum into family medicine residency training, this was actually a deterrent because the existing home visit requirement stipulated that visits occur with patients followed by residents in their continuity practice. Residents were unable to readily identify patients with developmental disabilities. A social worker was enlisted to help identify patients during year two, but the issue persisted. Elements of the PPHE curriculum that were easily integrated into the family medicine training program were the lectures, small group discussions, and clinical encounters at the Center for Development, Behavior, and Genetics.

Third year psychiatry residents participated in the PPHE program for one year, after the family medicine program pulled out. This was organized into a concentrated one-month rotation at the Center for Development, Behavior, and Genetics, similar to the first year PEDS rotation. Residents were assigned to the PPHE program for one half day per week during each four-week period. Two of the sessions were clinical experiences seeing patients with spina bifida and patients with autism under the supervision of developmental pediatricians at the Center for Development, Behavior, and Genetics. The agency visit was at a group home for patients with dual diagnoses. The home visit was arranged by the home visit coordinator and conducted jointly with the PEDS intern. Lectures were viewed on-line on the Blackboard site. Small group discussions were conducted jointly with the PEDS interns. Integration of the PPHE curriculum into the PSYCH training program was successful from the outset, and fostered inter-departmental collaboration on several other initiatives to better serve patients with dual diagnoses.

Getting Ready to Implement PPHE

SUNY Upstate participated in Phase II of the PPHE initiative, and thus was able to benefit from materials and ideas developed by Phase I programs. During the six-month planning phase, SUNY Upstate's project directors met with the project staff from St. Elizabeth's Family Medicine residency program, a Phase I PPHE grantee. Lecture materials and scheduling templates were generously provided, and a site visit by the Utica project manager was extremely helpful. The planning phase also included development of

community as well as resident advisory boards for the PPHE project. SUNY Upstate's administration was supportive from the outset, and provided assistance with publicity and promotion of the PPHE program both within Upstate and in the community at large. The 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.

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. Failure to fully integrate the PPHE curriculum into the FM and Third Year PEDS residency training can be attributed to two major factors: 1) PPHE elements were “diluted” over a 12 month period, rather than focused within a month-long rotation, and 2) lack of direct oversight by faculty in the outpatient clinics resulted in a less engaged resident cohort.

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, all PPHE activities were scheduled and transportation provided by a designated home visit facilitator.

Reflections. Gathering the residents' personal reflections was successful primarily because a brief (two page) template was provided at each home visit and residents were told to use this format for their small group discussions. However, it became apparent over time that residents spontaneously reflected on their home visit experience with the home visit facilitator on the ride home. Capturing these reflections on audiotape may be a better way to capture authentic reflections about the home visit 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.

Community medicine case presentations. It was a challenge to find a regular venue for community medicine case presentations outside the developmental pediatrics rotation. Small group discussions seemed more appropriate and worked well.

Community Agencies

The initial community partners were agencies already collaborating with Center for Development, Behavior, and Genetics 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. The Syracuse City School district in particular has been a very strong collaborator. The PPHE project fostered close and ongoing collaborations that have resulted in regular participation by faculty and residents in IEP meetings, integration of medical expertise into a school-based fitness program and

development and distribution of a DVD on collaboration and the IEP process based on the “School of Promise” model of inclusion. The Syracuse University Pro Bono Law Clinic and Family Advocacy Program has also been a strong partner. The Family Advocacy Project has broadened the array of services offered at the Center for Development, Behavior, and Genetics to include legal advocacy.

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 education and better outcomes for the individuals they serve.

Parents’ Recruitment

As noted previously, families served at the Center for Development, Behavior, and Genetics were recruited for the PEDS and PSYCH resident home visits. The PPHE project rapidly gained a reputation among families, and by the third year, parents were contacting the Center to ask about participation. Parents were offered \$100 for each encounter. Many families stated they would participate without compensation.

Unlike other PPHE programs, residents at SUNY Upstate did not follow families over time. Third year residents who had participated as interns met with a new family in their third year. This was primarily due to logistics of scheduling, to facilitate joint visits with PSYCH residents, and to distribute the opportunity to participate in home visit to an ever growing list of families who expressed interest in the PPHE project.

In one situation, a PEDS resident established a strong connection with a child who was medically fragile and who had been seen at a home visit. When the child was subsequently cared for in the emergency room, the parents contacted the hospital administration to express their gratitude for continuity of care provided by this resident. The parents stated that the resident on call in the emergency department quickly recognized the acute nature of the child’s illness because he knew her at baseline. Many 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

The Center for Development, Behavior, and Genetics was able to provide concentrated clinical experiences in developmental pediatrics to PEDS interns, PSYCH and FM residents. The Center is staffed by three developmental pediatricians, two nurse practitioners, two geneticists, two genetic counselors, several nurse specialists, several social workers, a nutritionist, and physical and occupational therapists. The Center is a regional referral center for children with autism, cerebral palsy, learning disabilities, blindness, spina bifida, and a wide variety of genetic conditions. Other clinical experiences that were provided included an off-site visit to Developmental Evaluation Center for children with autism, special education school and pre-school observations, and participation in team meetings at a model group home that serves youth with dual diagnoses. A key feature of the clinical experience for all PPHE residents was interdisciplinary training and cross-system collaboration.

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

- Dedicated home visit facilitator who arranges home visits, provides transportation, and models appropriate behavior during home visits. This position is key to the success of PPHE implementation. The home visit facilitator also provides safety and structure to the resident's home visits.
- Resident packets with sample of interview questions for the home visit as well as an outline for information to be gleaned from the agency visit. These steps help residents feel more comfortable in venturing out from the medical center. A home visit "etiquette tip sheet" is also useful.
- Debriefing of residents one-to-one shortly after the home visit. This is the time when "personal reflections" are most authentic.
- Using a single rotation for most PPHE activities works better than leaving the assignments open-ended. The PEDS intern developmental rotation and the PSYCH resident rotations were the most successful for this reason.
- Interdisciplinary training, with joint home visits and small group discussions for PSYCH residents and PEDS interns. This was a resounding success. The senior PSYCH residents were able to model interview skills for PEDS interns, and were excellent facilitators as well as participants in the small group discussions. The interdisciplinary model is particularly relevant to training of professionals who care for children and adolescents with dual diagnoses.

Sustainability

PPHE received institutional support from SUNY Upstate Medical University for publicity and marketing and from the Center for Development, Behavior and Genetics, the University Pediatric and Adolescent Center, and Departments of Family Medicine and Psychiatry for integration of PPHE into their respective educational programs for residents. In addition, the program received a great deal of support from community partners and family caregivers. By the end of the three years PPHE was well known in the community, and parents were asking for continued participation. The PPHE lectures are integrated into the pediatric lecture series, which is archived on SUNY Upstate's Blackboard website for residents. In addition, in 2008 the entire pediatric lecture series was distributed on DVD to community pediatricians. The hospital administration has seen the value of integrating the PPHE educational curriculum into the competencies of its trainees. PPHE fits into cultural competency training that the hospital is required to provide to the staff and residents. The PPHE curriculum also fits the "systems based care" requirement for pediatric residency certification. Finally, a major goal at SUNY Upstate is community outreach. PPHE has been very successful in this regard as well.

Integrating the goals of PPHE with the residency requirements is vital to the integration and sustainability of the program. This was most successfully accomplished during the developmental pediatrics rotation for first year PEDS residents. The home and agency visits will remain integrated within the developmental pediatrics rotation with division funding support and pro-bono participation by parents. For third year PEDS residents elements of the PPHE program will be integrated into a new clinical service that is being launched in fall 2009 to provide a medical home for children who are medically complex, many of whom have developmental disabilities. This program will be coordinated by the nurse practitioner who served as home visit facilitator and who is committed to continuation of home visits for clinical care and resident education. The FM residents and PEDS residents will continue joint training within the context of a joint PEDS/FM clinical service that will be launched in January 2010 to support youths with developmental disabilities as they transition from pediatric care to adult health services. PSYCH residents will continue to rotate at the Center for Development, Behavior, and Genetics as part of their clinical training.

Many community agencies have found the relationship with SUNY Upstate mutually beneficial. It gives agencies access to medical resources for the population they serve and an opportunity to educate physicians about the services they provide. In particular, a very strong collaboration has been established between the Center for Development Behavior and Genetics and the Syracuse City School District. Residents and faculty participate in IEP meetings with the city schools, and nurse managers at Upstate have regular contact with school nurses at several of the city schools. This is a direct outcome of the PPHE program. In addition, PPHE supported the development of a DVD about team collaboration between medical providers and school based professionals that will be distributed to parents, teachers, and residents for years to come. The Center for Development, Behavior, and Genetics will also continue to distribute the Exceptional Family Resources guide to community agencies and programs. PPHE has established strong linkages between medical services provided at SUNY Upstate Medical University and community based habilitation services. This collaboration improves health and social outcomes for children with developmental disabilities and is an excellent training experience for residents in pediatrics, family medicine, and psychiatry.

EVALUATION

Approach to Evaluating PPHE

DDPC's program staff, recognizing the importance of program evaluation, awarded a grant to COGME to provide technical assistance, sustainability planning, and overall evaluation for the projects, while requiring that each grantee 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.

It should be noted that the residents did not experience PPHE in exactly the same way, even though all four of the Phase II grants involved pediatric residency programs and involved the same PPHE curriculum. Sites differ for four basic reasons. First, there is a lot of flexibility in how a residency program meets- and often exceeds- ACGME requirements, allowing for diversity and innovation. Second, each site chose a model (one year, two year, or three year span for the PPHE elements) based on their view of how best to integrate PPHE into the existing curriculum. Maimonides implemented PPHE for first year residents. New York Medical College involved second and third year residents, SUNY-Upstate worked with first and third year residents. MSCHONY conducted PPHE for all three residency years. Third, there are differences in the knowledge, experience, and expectations according to residency year. Fourth, the number of residents affected the administrative ease of scheduling PPHE activities, such as home and agency visits. 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.



SUNY-Upstate also implemented PPHE in a family medicine residency program and a psychiatry residency. The family medicine program was highly motivated to integrate PPHE but existing programmatic requirements made it difficult. In this particular situation, some PPHE elements could be included while others could not. On the other hand, integrating the third year psychiatry residents into the pediatric version of PPHE was successful.

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 number of participants per site ranged from 26 to 60.

Comparison of Pretest and Post Scores

Percentages based on correct responses to multiple choice questions

Site	2006-07 Pretest –Post Test Scores	2007-08 Pretest - Post Test Scored	2008-09 Pretest – Post Test Scores
Maimonides	PGY1 50 - 60	PGY1 46 - 72	PGY1 41 - 79
MSCHONY*			PGY1 59 – 70 PGY2 65 – 86
New York Medical College	PGY 2 61 - 69 PGY 3 64 - 75	PGY3 69 - 74	PGY2 53 - 70 PGY3 54 - 79
SUNY-Upstate Pediatrics**	PGY2 56 - 66	PGY2 74 - 80	PGY1 72 - 75

*MSCHONY was delayed in collecting evaluation data due to issues getting IRB approval. The scores shown in 2008-2009 reflect pretests given in 2007-08 and post tests given in 2008-09. Because their PPHE model involved residents in all three years, the best option would have been to compare pretest scores from residency year one to post test scores in residency year 3. The data shown reflects change over two years.

** SUNY-Upstate and St. Joseph’s Hospital conducted PPHE for family medicine residents in 2006-07 and 2007-08. Data is available for only one year and is presented in the Evaluation chapter. SUNY-Upstate included psychiatry residents with their pediatric program in 2008-2009 but too few completed the pretest and post test to make the information useful.

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.

(I learned to) listen to what the parents/caregiver has to say,

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

My visit went fine. (The mother) was lovely. It was definitely enlightening to see what a tough time home life and simple tasks can be for a family with a PDD child.

Overall I had a good experience. I was struck by how many different resources need to come together in order to care for a child with disabilities.

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.

I think the biggest thing I took away from the experience was what an impact the words and tone a physician uses when giving a diagnosis has on the family and their general outlook towards the medical profession as a whole. The mother of this patient told me how awful it was to receive the diagnosis of Down syndrome since the doctor has been so adamant in stating that there was nothing to worry about and that everything was going to be fine. She said that the news would have been more bearable if the doctor had prepared them for the diagnosis.

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

The mother I visited was unrelenting in her quest to find the best for her daughter. She even went back to law school in order to learn to better develop a plan for when she and her husband are no longer able to care for their daughter.

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.

I learned about the challenges facing parents taking care of mentally disabled children in terms of finding support services, etc.

6. Despite the difficulties, families strive for normalcy.

(I learned that) children with developmental disabilities bring just as much joy as burden to their parents. I definitely need to learn more about resources available in the community.

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

Parents really want their PCP to be familiar with community resources. (This is covered in our readings and lectures, but it somehow sinks in more when I hear it from a parent.) Even when parents are high-functioning and take excellent care of their children, they still want and need support when dealing with schools and other agencies.

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

At times, I have been too busy and have not much time to talk to parents and the patient, how they feel and what their concerns are and how they think I can better provide the medical needs of their child.

It broadened my knowledge and perceptions about developmental disabilities beyond the medical visit/hospital stay interactions I previously had.

Attitude Change

The pediatric 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
- Confidence in their experience and ability to make referrals
- 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

The pediatric 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 for all three years, pediatric residents identified lack of experience and depth of knowledge as the number one and two impediments. On the post test, difficulties in coordinating care was listed as the number one impediment in two years and time constraints as the number one impediment in the third year.

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. Data is available for only one year of the family medicine program conducted by SUNY-Upstate. Pretest and post test scores on questions of fact did not change. On the post test: 56 percent felt adequately trained to do screening, compared to 28 percent who felt adequately trained to do screening on the pretest; 56 percent reported feeling comfortable managing screening, compared to 16 percent who said they felt comfortable on the pretest. There was no change on the percentage who said the “should manage screening” or “want to manage screening.”

Also on the post test: fewer family medicine residents thought insufficient depth of knowledge and lack of experience were impediments to providing care. They continued to see difficulties coordinating care, difficulties referring to specialists or time constraints as problems. Opinions about the seriousness of language barriers as impediments to care were unchanged.

Conclusions

Based on the three-year Phase II 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 (e.g., 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 start-up 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.

- Resident “buy in” to the program is essential. Given the pressures and demands of residency requirements, residents need see the value of and participate in the management of PPHE. Their input can solve or avoid problems.
- 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.