

# Parent Partners in Health Education

Resident Curriculum in  
Developmental Disabilities

July 2007

# PPHE at CHONY

- **Funding: New York State Developmental Disabilities Planning Council**
  - 2006-2009 grant period
- **Start-up: July 2006**
  - Pediatric Residents
  - July 2007 for Family Practice Residents on a limited basis
- Must follow PPHE model curriculum (originally developed for Family Practice residents in Illinois)

# Goals

- **Broaden residents' knowledge about developmental disabilities.**
- **Increase their skills in identifying children with developmental disabilities and accessing appropriate community resources.**
- **Change providers' attitudes and perceptions about children with developmental disabilities.**

# Partnerships

- **At the heart of the program is the formation of a *partnership* between the *resident* and the *family* of her/his own patient who has a developmental disability.**
- **The partnership is forged by the beginning of the resident's 2<sup>nd</sup> year and continues until the end of his/her residency.**

# Choosing a partner family Residents:

- **You should have several continuity clinic patients with developmental disabilities by the beginning of the 2<sup>nd</sup> year.**
- **Prior to your outpatient or community pediatrics block (whichever comes first,) discuss the PPHE program with your patient's parent, using the PPHE brochure. You may need to approach several parents to find one who is interested and available.**
- **Your home visit time is automatically scheduled into the block, but can be changed if inconvenient for the parent. Notify us when you have identified your parent partner/family.**

# What is a Developmental Disability?

The term "**Developmental Disability**" means a severe, chronic disability of an individual that:

- 1. is attributable to mental or physical impairment or combination of mental and physical impairments;**
- 2. is manifested before the individual attains the age of 22;**
- 3. is likely to continue indefinitely;**
- 4. results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency;**
- 5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.**

# What are special health care needs?

- **Children with special health care needs are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (AAP, Pediatrics 102:1, Jul 1998)**

# Choosing a patient for partnership

## **Appropriate:**

- **Mental retardation**
- **Cerebral palsy**
- **Ex-premie with IVH**
- **Autism**
- **Spina bifida**
- **Schizophrenia**

## **Inappropriate:**

- **18-month old with mild language delay**
- **Congenital heart disease without sequelae**
- **Cystic fibrosis**
- **Diabetes**

# NYS Grant Objectives

- **Integrate core components of PPHE into the residency program**
- **Measure changes in residents' knowledge, attitudes, and skills in working with children and adults with developmental disabilities**
- **Obtain ongoing funding for the program beyond the 3 year grant**

# Council on Graduate Medical Education

- **COGME working with NYS DDPC to evaluate efficacy of program**

Has created specific evaluative material that will be used here

- **If successful, COGME may mandate inclusion of PPHE curriculum in all NYS residency programs**

# PPHE Curriculum

- **Four didactic lectures (most take place within continuity clinic conference time)**
  - Program introduction (this is it!)
  - Denver Developmental screening
  - Legal and advocacy issues
  - Doctor—family communication
- **Home visits**
- **Community Agency visits**
- **Small group discussions**
- **Community Pediatrics presentations**

# Resident Curriculum through 3 years:

- **1<sup>st</sup> year:**
  - Attend didactic presentations in clinic
  - Participate in small group discussions in clinic
  - Attend Community Pediatric presentations (given @ Chief of Service rounds)
  - Choose parent partner by end of 1<sup>st</sup> year
- **2<sup>nd</sup> year:**
  - Visit partner family at home, once with Project DOCC parent guide, once with Community Pediatrics faculty guide.
  - Attend didactic and Community Pediatric presentations
  - Participate in small group discussions in clinic
- **3<sup>rd</sup> year:**
  - Attend didactic and Community Pediatric presentations
  - Visit community agency with partner family
  - Participate in clinic small group discussions
  - Present partner family experiences @ Chief of Service rounds in 2<sup>nd</sup> half of year (2 selected 3<sup>rd</sup> year residents)

# Denver Developmental Didactic

- **Dr. Harriet McGurk's regular continuity clinic presentations**
- **Will be given September-October**
- **No power point presentation on website**
- **More Denver during Developmental block**

# Advocacy/Legal Didactic

- **Given November-December by Continuity Clinic Preceptor**
- **On Community Pediatrics website**
- **Has useful internet links to relevant New York City agencies**

# Doctor-Family Communication Didactic

- **Currently part of Cultural Competency Curriculum**
- **April 2008, for 1<sup>st</sup> and 2<sup>nd</sup> year residents**

# Home visits

(2<sup>nd</sup> year residents)

- **Community Peds Block**

- **Guided by Project DOCC parent: each is a parent of a child with special health care needs who is experienced in conducting residents on home visits.**

- **Ambulatory Block**

- **Guided by Community Peds faculty (merged with Gold Foundation home visits)**

# Community Agency visit

(3<sup>rd</sup> year residents)

- **Resident goes to patient's appointment at community agency during Outpatient block**
  - **Early intervention therapy or evaluation session**
  - **School day in special ed program**
  - **Specialty clinic appointment!!?!!**
  - **Special ed evaluation**
  - **Camp, therapy, support group, others**

# Small group discussions

- **Take place during continuity clinic conferences, and have narrative medicine format.**
- **Focus on 3<sup>rd</sup> year resident's experiences during the home and community agency visits, and the resident's overall partnership with the family.**
- **One session per resident.**

# Community Peds Presentation

(3<sup>rd</sup> year residents)

- **Chief of Service rounds presentations by at least two 3<sup>rd</sup> year residents.**
- **Any 3<sup>rd</sup> year resident who is interested may choose to do his/her Chief of Service presentation on his/her PPHE patient and family, discussing any aspect of the child's disability and family/community involvement.**

# Evaluations

- **Residents:**

- **Pre-test: to be completed along with this introductory lecture**
- **Post-test: to be completed at end of each year**
- **Didactic lecture evaluation**
- **Reflection cards (on OutPt and Comm Peds blocks)**
- **Community Peds Presentation evaluation**
- **Year-end PPHE evaluation**

- **Preceptors: no specific evaluation**

- **Parent Partners:**

- **To be completed after community agency visit**