Children with Disabilities Pediatric Rotation

Orientation Manual to the Three-Year Residency Training Curriculum

Developed by:

University of Connecticut

A.J. Pappanikou Center for Developmental Disabilities

CONTENTS:

INTRODUCTION

Physicians and other health care providers are often the first people parents speak with when they are concerned about the development of their children. Thus, the pediatrician or primary health care provider is often the critical entry point for families with children with special needs. Parents turn to the pediatrician to access information, resources, and services that will address their children's needs and enhance their development in all realms. Meeting the needs of children with disabilities and/or special health care needs is a complex process for all involved. It requires highly refined skills in communication, coordination, and collaboration and a close partnership between parents, other family members, primary care physicians, other health care providers, and service providers. When fully realized, these collaborative efforts enhance the care provided to children and improve outcomes for children and their families.

Physician training is beginning to incorporate a more comprehensive, coordinated, system-based model of care that defines how services should be provided within the context of the family's needs. The American Academy of Pediatrics (AAP) has been active in the development of comprehensive medical education programs. In 1978, a specialty task force released a report on pediatric education (The Task Force on Pediatric Education, 1978). This task force assessed the health needs of children with disabilities and the educational needs of the pediatricians who assess these children. Among the conclusions of the task force were that pediatricians need to:

1) Develop skills for coping with biosocial and developmental problems.
2) Gain skills for improving interpersonal and professional approaches toward children with disabilities and their families.
3) Improve and increase participation on interdisciplinary teams.

Finally, the task force concluded that residency programs need to emphasize training in the provision of care to children with chronic handicapping conditions.

The AAP has developed various training materials for use with physicians and others involved in providing services to children with disabilities. Most recently, the AAP published guidelines to support the role of the pediatrician in the development and implementation of programs for children receiving early intervention or special education services (Committee on Children with Disabilities, 1992). Additionally, the Ambulatory Pediatric Association (APA) has incorporated goals and learning objectives for working with children with disabilities and their families into the Educational Guidelines for Residency Training in General Pediatrics (Kitteredge, 1996). A number of medical schools around the country have also been effortful in expanding

physicians7 knowledge base about children with disabilities from a preservice perspective at residency and post-residency (fellowship) levels. Finally, the AAP has endorsed the concept of a "medical home" in which comprehensive, coordinated, family-centered, and community-based primary medical care is provided for each child.

As more children survive because of advanced medical technology, it has become apparent that the role of the health care provider must be integrated into a child's early intervention or special education program. The role of the pediatrician or family physician in early intervention and special education is well supported in literature (Blackman, Healy, & Ruppert, 1992; Brewer, McPherson, Magrab, & Hutchins, 1989; Committee on Children with Disabilities, 1992; Coury, 1990; Howard, 1982; Mclnerny, 1984; Peter, 1992; Shonkoff, Dworkin, & Leviton, 1979; Solomon, 1995; Teplin, Kuhn, & Palsha, 1993). Early intervention law (Part H, renamed Part C under the 1997 reauthorization of the Individuals with Disabilities Education Act or IDEA) supports the integral role of the physician in providing medical care for diagnoses and health services that enable children (birth through 2 years old) to benefit from early intervention. Likewise, provisions in Part B of IDEA regard health services as a "related service" to address health care needs that impact learning and to enable children (3 through 21 years old) to benefit from special education intervention.

The physician who provides medical care to a child with disabilities plays a key role in the ongoing support of the child and his or her family and as a member of the intervention team. Federal law acknowledges the importance of related health services by including physicians as participants within the statewide system of early intervention. In reality, however, there are few states where health care and the pediatrician or family practice provider are well integrated into the statewide system. As a child ages into the special education system (ages 3-21), the gap between the child's medical care and educational services only increases.

It is suggested that possible reasons for this situation are a lack of awareness and knowledge on the part of physicians about their role in early intervention and special education systems and the lack of emphasis placed on the care and management of a child with disabilities throughout the preservice and inservice training of pediatricians.

The University of Connecticut A.J. Pappanikou Center for Developmental Disabilities has been involved in planning, developing, implementing, and evaluating training materials and activities in early intervention and special education for medical students, pediatric residents, and practicing physicians since 1992. As a

result of these experiences and the impetus of the AAP, the APA, and federal and state government, the UConn Pediatric Residency Program instituted a new curriculum organization effective July 1, 1996. The Children with Disabilities Rotation at Connecticut Children's Medical Center is an outgrowth of these initiatives.

This orientation manual is designed to provide an overview of the goals and components of this project and a description of the roles and responsibilities of the interns, residents, faculty preceptors, and project staff.

GOALS

The purpose of the pediatric rotation on children with disabilities is for residents to increase their awareness about the impact that disabilities and special health care needs have on children and their families and to learn methods for providing comprehensive, coordinated, community-based, and family-centered health care to these children and families. As a result, children and families, as well as early intervention and special education programs, will benefit from the resident's active participation during the training program and after they graduate into practice.

At the completion of the Children with Disabilities Pediatric Rotation, you, the pediatric resident, will have:

1) Increased your understanding in communicating with children with disabilities and their families.
2) Acquired knowledge and skills that will enable you to address the medical, social, educational, and emotional issues affecting children with disabilities and their families.
3) Increased your ability to provide appropriate and effective primary medical care to children with disabilities and/or special health care needs within private, hospital, or community settings.

Outcomes in these goals will be demonstrated on the *Resident Self-Evaluation, Pre and Posttests, and Performance Rating by Preceptor* forms. We understand that the experiences embedded in this curriculum may not be replicated in a day-to-day medical practice. However, participation in these experiences will provide you with a unique set of skills and additional knowledge that will, hopefully, profoundly influence how you practice pediatric medicine. In particular, they will enhance your awareness of children with disabilities and their families and will help you to discover ways to interact with the children, their families, and the systems with which they are involved.

CURRICULUM COMPONENTS

The longitudinal curriculum for the Children with Disabilities Pediatric Rotation is designed to build conceptually from simple to complex knowledge, from basic information to guided practice, and finally from mastery of knowledge to application and refinement of expertise through collaboration, consultation, and advocacy. All pediatric residents are required to complete the competencies and practicum experiences contained within this curriculum.

The curriculum is divided by year with, on average, two learning modules to be completed in each of the three years for a total of six learning modules. The modules are designed to be used in sequence and the content moves conceptually from family systems to community systems and, finally, to state and national systems. The rotation schedule is located in Appendix A. The curriculum has been altered slightly to accommodate the internal medicine/pediatric resident's schedule. This rotation schedule can be found in Appendix B.

In designing this curriculum, we have attempted to adhere to best practices in adult learning. Medical and educational personnel have worked closely on this curriculum to assure that the goals, objectives, and training experiences are realistic, relevant, and valuable for developing awareness and skills for providing care to children with disabilities and their families. The learning and practicum experiences require active participation and will be tailored as much as possible to meet the individual needs and interests of each resident. Readings and video presentations are used to reinforce the concepts that are taught. Finally, the evaluation materials and debriefing sessions provide frequent opportunities for feedback and reflection both during the learning process and upon completion of each module.

TIME REQUIREMENTS

Each resident will spend, on average, 13 half days per year spread across the ambulatory practice block. This works out to approximately four half days per block (barring vacations) during all three years of the residency training program. Residents receiving dual training in general medicine and pediatrics will spread this rotation over four years of residency. The half days will involve both didactic sessions and practicum experiences as described below.

INSTRUCTIONAL MODULES

The curriculum contains six instructional modules. The modules will be distributed at the beginning of each year. The modules cover the following topics:

Year 1	Year 2	Year 3
Family-Centered	Team-Based Service	Advocacy & The

Care	Models	Legislative Process
Early Intervention	Interagency Collaboration, Service Integration, and Resource Allocation	
Special Education		

MODULE CONTENTS

Each module is divided into two or more components and contains some or all of the following:

- An introduction to the topic.
- A description of the organization of the components within the module.
- Objectives that are expected to be mastered upon completion of the module.
- Background information, history, guiding principles, and theory.
- A family study with discussion questions, answers, and resolution.
- Practicum experiences (see below).
- Evaluative materials.
- References and further readings.

DIDACTIC EXPERIENCES

At the beginning of each module there is a didactic session. These sessions entail a review of the content and practicum experiences for that module, as well as dialogues between the resident and project staff about the topic, readings, and the family study. Efforts will be made to apply learning experiences to children and families you are currently seeing in continuity clinic or have seen in the past.

PRACTICUM EXPERIENCES

Each learning module contains practicum experiences that are designed to provide you with an opportunity to apply what you have learned during the didactic session and readings.

For each practicum experience there are specific expectations, guidelines, and written evaluation materials contained within the module. **You must review the *Guidelines* and the *Resident Self-Evaluation* form prior to the practicum experience.** Practicum experiences include:

- **Home visits:** You will visit the families of children with disabilities and/or special health care needs in each of the families homes. Initially, you will be matched with a family by the project staff. Eventually, all residents will identify families through their continuity clinics. Ideally, this should be

done as early as possible during the first year of the residency program. (Please see *Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs* in Appendix C of this manual).

- **Program visits:** You will observe a variety of programs and specific children within programs. These observations include early intervention community-based services and elementary, middle, or high school programs.

- **Attendance at specialty clinics:** You will participate in several specialty clinics during the three years of the curriculum. Experiences may be selected from the following specialty clinics:
  - Adaptive Equipment Specialty Clinic
  - Cardiology
  - Cerebral Palsy
  - Craniofacial
  - Diabetes
  - Genetics
  - Hematology and Oncology
  - Hospital for Special Care
  - Muscle Disease
  - Myelomeningocele
  - Neurology
  - NICU Follow-up
  - Pulmonary, including Bronchopulmonary Dysplasia and Cystic Fibrosis

- **Observation of assessments:** You will observe a child being assessed in two different disciplines. These may include occupational therapy, physical therapy, speech therapy, and audiology.

- **Observation of and participation in team meetings:** You will observe and participate in various team meetings, including specialty clinic and continuity clinic meetings and Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP) meetings.

- **Observation of and participation in community meetings:** You will observe and participate in various community meetings, including local or state interagency collaborating council meetings, advisory board meetings, and legislative sessions.

- **Interviews:** You will have the opportunity to interview families, a legislator, and an agency administrator.

- **Advocacy projects:** During the final block of the third year you will design an independent project based on your own specific area of interest.

Backup Plan: If for any reason a practicum experience cannot be arranged, is canceled, or if no patient is available in a specialty clinic, the resident should immediately call the project coordinator at the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities.

INDIVIDUAL PORTFOLIO

Each resident must develop and maintain an individual portfolio. The portfolio will be a compilation of material gathered throughout the three years of residency. For example, you might include a pamphlet that you received at a practicum experience, or you might include research articles or agency information. You may also choose to write about a particular visit and place reflections and anecdotes in your portfolio. It is expected that once you are in practice, the items in your portfolio will be useful as resource materials for your patients with disabilities and their families. The portfolio should be brought to each biannual debriefing for review.

IDENTIFYING CHILDREN WITH DISABILITIES AND/OR SPECIAL HEALTH CARE NEEDS

Appendix C contains the *Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs within the Continuity Rotation*. These guidelines are designed to assist you in identifying children who may be eligible to receive or are already receiving early intervention or special education services.

The purpose of identifying eligible patients is to enable you to:

- Follow children with disabilities and/or special health care needs in the continuity clinic through the entire three years of the residency program.
- Apply the learning experiences from the Children with Disabilities curriculum to patients seen in continuity clinic.

- Provide comprehensive and coordinated care to patients with disabilities and/or special health care needs.

Additionally, you should always ask in the initial interview with a new patient whether the child has received any services through Birth to Three or special education.

EVALUATION MATERIALS

- **Progress file:** These will be maintained for each resident and kept at the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities. These files will contain a record of competencies completed by each resident, all completed evaluation materials, and the biannual resident review. A copy of this review will also be placed in the resident's file at Connecticut Children's Medical Center.

- **Pretests:** There is a pretest for each module to assess your knowledge level of the topic prior to completing each of the learning activities.

- **Session satisfaction surveys:** These are completed after each didactic session and provide opportunity for you to voice your satisfaction with the session and provide feedback to project staff.

- **Debriefing sessions:** Discussion/debriefing sessions will be held with project staff or preceptors after practicum experiences.

- **Resident self-evaluations:** These are completed after each practicum experience. Self-evaluations are designed to enable you to process what you have learned during practicum experiences, apply knowledge you have attained during the didactic session, problem solve, and anticipate how these learning experiences may impact your practice. They also provide an opportunity for you to evaluate what the practicum experience meant to you and to provide feedback to project staff about this experience.

- **Performance ratings by preceptors:** These are completed after each practicum experience, including the didactic session, and provide an opportunity for the preceptor to evaluate the performance, strengths, and weaknesses the resident demonstrated during the practicum experience. Preceptors include specialty clinic faculty, teachers, early interventionists, therapists, team

participants, family members, and project staff, including the medical consultant, depending on the specific practicum experience.

- **Module satisfaction surveys:** These are completed after each module and are designed to provide you with an opportunity to give feedback about what you have learned during that module.

- **Posttests:** The posttests are the same as the pretests and are to be completed after each module. They are designed to assess an increase in your knowledge of the topic after completing each of the learning activities.

- **Annual evaluation:** Each resident will meet with the project staff once a year to review the progress file and the individual portfolio. A written evaluation will be completed. A copy of the evaluation will be placed in your file at the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities and at Connecticut Children's Medical Center.

EVALUATION SCHEDULE

Instrument	When to Complete	Who to return it to
Pretests	Prior to each didactic session	Project coordinator or session preceptor
Posttests	Upon completion of each module	Project coordinator
Session satisfaction surveys	Upon completion of each didactic session	Project coordinator or session preceptor
Self-evaluations	Upon completion of each practicum experience	Project coordinator
Performance ratings by preceptor	Upon completion of each practicum experience, including the didactic session	Project coordinator
Module satisfaction surveys	Upon completion of each module	Project coordinator or session preceptor
Annual evaluation	Annually by the project staff	Project coordinator

RESPONSIBILITIES

- Residents:
    - Attend all didactic sessions and practicum experiences at scheduled times.
    - Bring necessary evaluation forms.

- Participate in all discussions.
- Identify children in continuity clinic as early as possible during the rotation.
- Schedule home visits and interviews with continuity clinic families and service providers.
- Review *Guidelines* and *Self-Evaluation* forms prior to all practicum experiences, home and program visits, team meetings, etc.
- Complete independent reading related to specialty clinic areas.
- Conduct interviews with families, team members, program preceptors, etc.
- Participate in all debriefing meetings.
- Complete *Self-Evaluation* form for each practicum experience.
- Return all *Self-Evaluation* forms to the project coordinator.
- Provide appropriate *Performance Rating* forms to a family member or preceptor for each practicum experience.
- Work with project coordinator to develop advocacy project for third year of residency.
- Complete the *Advocacy Project Proposal* form.
- Develop and maintain individual portfolio.
- Participate in annual evaluation sessions with the project staff.

❖ Project Staff:

- Provide orientation training and *Orientation Manual* to all residents.
- Provide instructional modules to all residents for each year of the residency training.
- Coordinate with medical personnel to schedule residents for all sessions during each block of the rotation.
- Schedule all practicum experiences, including specialty clinics, program visits, team meetings, agency meetings, etc.
- Review objectives and conduct didactic sessions for each module.
- Complete family study examples with residents during each didactic session.
- Review *Guidelines* for each practicum experience with the resident.
- Facilitate debriefing sessions after practicum experiences.
- Attend program visits with the residents, when possible.
- Maintain a progress file for each resident, which includes ensuring that all evaluation forms have been completed, returned, and filed.

- Identify and maintain communication with all program sites (schools, community-based services, etc.).

❖ Preceptors*:

- Provide opportunities for residents to participate in the practicum experience with appropriate support and guidance.
- Select and introduce the resident to a family who has an appointment for that day (for specialty clinics only).
- Facilitate debriefing sessions.
- Complete *Performance Rating* forms for each resident after the practicum experience.
- Maintain ongoing communication regarding project activities with the project coordinator, medical consultant, and other project staff.

***Note:** *"Preceptor" includes Connecticut Children's Medical Center medical/acuity, teachers, early interventionists, therapists, team participants, family members, and project staff, including the medical consultant.*

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APPENDICES

A: Rotation Schedule

B: Rotation Schedule for Internal Medicine/Pediatric Residents

C: Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs within the Continuity Clinic

APPENDIX A

Rotation Schedule

	Component	Curriculum Content
YEAR 1	**Module One: Family-Centered Care**	
	1	Orientation/Introduction to Family-Centered Care
	2	Home visit arranged through the Univ. of CT A.J. Pappanikou Center
	3	Home visit with patient from continuity clinic
	4	Specialty clinic visit
	Module Two: Early Intervention	
	1	Introduction to Early Intervention
	2	Observation of an early intervention program-home-based services
	3	NICU follow-up clinic visit
	4	Observation of an early intervention program-community-based services
	Module Three: Special Education	
	1	Introduction to Special Education
	2	Observation of special education program in elementary, middle, or high school
	3	Early intervention or school visit with patient from continuity clinic
	4	Specialty clinic visit
YEAR 2	**Module Four: Team-Based Service Models**	
	1	Introduction to Team-Based Service Models
	2	Observation of assessment or intervention (PT, OT, SP, Audiology) followed by interview with the interventionist
	Module Five: Interagency Collaboration, Service Integration, and Resource Allocation	
	1	Introduction to Interagency Collaboration, Service Integration, and Resource Allocation
	2	Advocacy project discussion and proposal
	3	Family interview on integrated care and funding sources
	4	Agency administrator interview
	5	Open for catch-up visit, advocacy project guidance, or resident's area of special interest
Y	**Module Six: Advocacy and the Legislative Process**	
	1	Introduction to Advocacy and the Legislative Process
	2	Observation of a legislative hearing, public hearing, or task force meeting

E A R 3	3	Meeting with a legislator
	4	Observation of state interagency collaborating council or advisory council meeting
	5	Advocacy project
	6	Advocacy project
	7	Advocacy project
	8	Recap/closure

APPENDIX B

Rotational Schedule For Internal Medicine/Pediatric Residents

	Component	Curriculum Content
Y E A R 1	**Module One: Family-Centered Care**	
	1	Orientation/Introduction to Family-Centered Care
	2	Home visit arranged through the Univ. of CT A.J. Pappanikou Center
	3	Specialty clinic visit
	Module Two: Early Intervention	
	1	Introduction to Early Intervention
	2	Observation of an early intervention program-home-based services
Y E A R 2	**Module Three: Special Education**	
	1	Introduction to Special Education
	2	Observation of special education program in elementary, middle, or high school
	3	Early intervention or school visit with patient from continuity clinic
Y E A R 3	**Module Four: Team-Based Service Models**	
	1	Introduction to Team-Based Service Models
	2	Observation of assessment or intervention (PT, OT, SP, Audiology) followed by interview with the interventionist
	3	Participation in a team meeting (specialty clinic, continuity clinic, IFSP, IEP)
Y E	**Module Five: Interagency Collaboration, Service Integration, and Resource Allocation**	
	1	Introduction to Interagency Collaboration, Service Integration, and Resource Allocation
	2	Family interview on integrated care and funding sources

A	3	Agency administrator interview
R	**Module Six: Advocacy and the Legislative Process**	
4	1	Introduction to Advocacy and the Legislative Process
	2	One visit to the State Capitol-either observation of a legislative, public hearing, or task force meeting or meeting with a legislator
	3	Observation of state interagency collaborating council or advisory council meeting
	4	Recap/closure

APPENDIX C

Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs within the Continuity Clinic

While this list is not all inclusive, the following are possible factors that may indicate a disability and the need for referral to early intervention (birth through age two) or special education (ages three to twenty-one) services:

- **Prenatal history:**
  - Maternal illnesses: e.g., infectious diseases, conditions such as diabetes or PKU
  - Abnormal prenatal test results: triple screen (AFP), amniocentesis, ultrasound
  - Exposure to teratogens
  - Substance abuse: alcohol, cocaine, heroin, other controlled substances
  - Pedigree: family history of learning disabilities, mental retardation, specific inherited disorders

- **Birth history:**
  - Complications to newborn: e.g., meconium aspiration, intrauterine growth retardation, neonatal sepsis, prematurity, postmaturity, respiratory distress, low birth weight
  - Admission to Neonatal Intensive Care Unit (NICU)
  - Congenital abnormalities

- **Newborn period:**
  - Failure to thrive

- Need for medication or medical intervention: ventilation, NG feeding
- Oral motor difficulties: e.g., poor feeding or sucking
- Regulatory difficulties: e.g., temperature regulation
- Abnormalities in muscle tone: hypertonia, hypotonia
- Involvement of any specialty medical care

❖ **At any age-functional delays in combination with any one of the following complications:**

- Need for adaptive devices or assistive technology: e.g., ankle-foot orthosis, communication board, wheelchair
- Child abuse
- Chronic condition or illness: e.g., congenital heart disease, cancer, HIV
- Exposure to toxins: e.g., lead
- Gastroenterology: reflux, need for G-tube
- Congenital, genetic, or inherited disorders
- Hospitalizations or surgeries
- Neurologic disorders or dysfunctions: seizure disorder, traumatic brain injury
- Recurrent ear infections, cleft palate
- Pulmonary: asthma, cystic fibrosis
- Rheumatology: juvenile rheumatoid arthritis, Ehlers-Danlos syndrome
- Sensory impairments: hearing, vision
- Sociocommunicative disorders: autism, pervasive developmental disorder

❖ **General concerns in child development:**

- Any concerns raised by parents, family members, daycare providers, or teachers
- Attention and concentration
- Behavioral or emotional difficulties, including reactivity to changes in environment, stress
- Child abuse
- Cognitive development/thinking skills
- Communication skills, including speech/articulation, understanding language, expressing self
- Fine and gross motor skills, coordination
- Learning disabilities

- Processing sensory information: e.g., hypersensitivity to sound, hyposensitivity to pain (increased threshold)
- Self-care and daily living skills
- Social skills and play skills

❖ **Involvement with:**

- Birth to Three/early intervention services
- Special education services through the public school system

❖ **Involvement with other agencies:**

- Board of Education and Services for the Blind (BESB)
- Children with Special Health Care Needs (Title V)
- Department of Children and Families (DCF)
- Department of Mental Retardation (DMR)
- Department of Social Services (DSS), including any medical waiver programs
- Psychotherapists, family therapists, social workers
- Supplemental Security Income (SSI)
- Visiting Nurse Association (VNA)