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ABSTRACT

This final report describes the activities and outcomes of a project designed to develop, implement, and evaluate a new three-year longitudinal competency based curriculum for pediatric residents on their role in early intervention and special education. The curriculum consisted of four half-days per month for every resident in an ambulatory primary care block (4 months/year/resident) during their three years of training. The curriculum components included observation and participation in clinical care for children with disabilities at the Connecticut Children's Medical Center, participation in home visits for children with disabilities, observations of children in early intervention and special education settings (either natural environments or inclusionary settings), observations and participation in Individualized Family Service Plan and Individualized Education Program meetings, coordination and evaluation of health related services, and participation in state or local planning task forces in early intervention and special education. Written materials, manuals, and an evaluation model using individual portfolios documenting competencies associated with this curriculum were developed as part of the project. The report includes a discussion of project goals and objectives, the theoretical and conceptual framework of the project, the training model, and the impact of the project. Extensive appendices are included. (Contains 64 references.) (CR)

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Grants for Preservice Personnel Training
CFDA: 84 029G

Component 2: Preparation of Related Services Personnel
34 CFR 318.11(2) Pediatric Residents

Final Report

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Abstract

Training Personnel for the Education of Individuals with Disabilities Program
Grants for Preservice Personnel Training
CFDA: 84 029G

Component 2: Preparation of Related Services Personnel
34 CFR 318.11(2) Pediatric Residents

This preservice personnel preparation project at the University of Connecticut School of Medicine developed, implemented and evaluated a new three year longitudinal competency based curriculum for pediatric residents on their role in early intervention and special education. The curriculum consisted of four half days per month for every resident in an ambulatory primary care block (4 months/year/resident) during their three years of training. The curriculum components included observations and participation in clinical care for children with disabilities at the Connecticut Children's Medical Center, participation in home visits for children with disabilities, observations of children in early intervention and special education settings (either natural environments or inclusionary settings), observations and participation in IEP and IFSP meetings, coordination and evaluation of health related services, and participation in state or local planning task forces in early intervention and special education such as the Interagency Coordinating Council (local and state), or special education advisory boards. Written materials, manuals and an evaluation model using individual portfolios documenting competencies associated with this curriculum were developed as part of the project. Each year, 13-15 residents entered the pediatric program, and the project began by providing the curriculum to 39 residents. Thereafter the residents progressed on a yearly basis through modules on early intervention and special education which included: the family, history and laws, the IFSP and IEP team process, coordination of related services, advocacy at a family, local program and system level. The competency based curriculum served as one component of new educational guidelines developed by the Ambulatory Pediatric Association which were approved by the Residency Review Committee of the Accreditation Council for Graduate Medical Education. Ninety-two pediatric residents progressed through the curriculum during the three years of the program.

TABLE OF CONTENTS

Page

APPENDICES

APPENDIX A
    Project Staff Vitae

APPENDIX B
    Bibliography

APPENDIX C
    Past Experience Form

APPENDIX D
    Medical Consultant's Job Description--Year 3

APPENDIX E
    Additions to Curriculum:
    Articles From the American Academy of Pediatrics
    Hospital for Special Care Forms and Addendum Articles
    Adaptive Equipment Specialty Clinic Forms and Addendum Material
    NICU Follow-Up Specialty Clinic Addendum Articles

APPENDIX F
    Sample Module: Family Centered Care

APPENDIX G
    Orientation Manual

APPENDIX H
    Session Information Form
    Resident Evaluation Forms

APPENDIX I
    Debriefing Summary Report

APPENDIX J
    Sample Outreach Meeting Records

APPENDIX K
    Advocacy Projects

APPENDIX L
    Example Sessions with Legislative Consultant
    Legislative Consultant Meeting Records

TABLES

Project Goals and Objectives

Objective	**1.0**	**Develop a preservice personnel preparation program**
	1.1	Assess training needs
	1.2	Convene advisory board
	1.3	Meet with project consultant
	1.4	Refine curriculum content
	1.5	Refine methodology
	1.6	Refine competencies
	1.7	Organize and schedule clinical practica
	1.8	Develop training manuals, materials, and evaluation instruments
	1.9	Recruit and admit students
	1.10	Schedule modules, seminars and meetings
Objective	**2.0**	**Implement a preservice personnel preparation program**
	2.1	Implement modules
	2.2	Utilize home and school visits
	2.3	Utilize instructional technology
	2.4	Implement seminars
	2.5	Supervise clinical practica
	2.6	Implement state
	2.7	Convene Higher Education Council
	2.8	Facilitate competencies
Objective	**3.0**	**Evaluate a preservice personnel preparation program**
	3.1	Evaluate student status
	3.2	Evaluate program status
	3.3	Evaluate community status

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Theoretical and Conceptual Framework

The purpose of this project was to develop, implement and evaluate two new preservice personnel preparation programs at the University of Connecticut School of Medicine. The programs were administered by the Department of Pediatrics, Division of Child and Family Studies. The first program (hereafter referred to as Component 2) was the Preparation of Related Services Personnel (34 CFR 318.11(2)). The goal of this program was to prepare pediatric residents to provide appropriate and effective supportive (related) services in early intervention and special education. The goal of the second program (hereafter known as Component 3) was the preparation of Early Intervention and Preschool Personnel (34 CFR 318.11(3)).

Both of these programs were new preservice personnel preparation programs. Both were interdisciplinary, competency based, and focused on the improvement of early intervention and special education services in Connecticut. This final report addresses the first program only, component 2. A separate final report is being written for component 3.

COMPONENT 2 - RELATED SERVICES: PEDIATRIC RESIDENTS

Significance. The role of the physician in early intervention and special education has been one that could be improved upon from a variety of perspectives. Early intervention law (Part H of IDEA, now Part C) supports the integral role of the physician in providing medical services for diagnosis and health services to enable the child to benefit from early intervention. Likewise, IDEA provisions for children from age three to twenty-one regard health services as a related service to enable a child to benefit from special education. As more children survive because of advanced medical technology (e.g., feeding tubes; ventilators), 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. In order to facilitate this integration of a child's needs across both the educational and medical disciplines, training must be provided.

The role of the pediatrician or family physician in early intervention and special education has been addressed in the literature (Blackman, Healy, & Ruppert, 1992; Brewer, McPherson, Magrab, & Hutchins, 1989; Committee on Children with Disabilities, 1992; Coury, 1990; Howard, 1982; McInerny, 1984; Peter, 1992; Shonkoff, Dworkin, & Leviton, 1979; Solomon, 1995; Teplin, Kuhn, & Palsha, 1993). The physician who provides medical care to a child with disabilities plays a key role in the ongoing support of the child and his/her family, and intervention team. Federal law acknowledges the importance of the physician and health services by including them as components within the statewide system of early intervention. In reality, however, there have been few states where the health system, and the pediatrician or family practice provider, are well integrated into the statewide system. As a child ages into the special education system (age 3-21) the gap between the child's medical care nd educational services only increases (Eaton, Coury, & Kern, 1989). **It has been suggested that one reason for this situation is a lack of awareness and knowledge on the part of physicians about their role in systems of early intervention and special education.** This is not surprising considering that there has been very little emphasis placed on the care and management of a child with disabilities throughout both the preservice and inservice training of pediatricians (Scott, Lingaraju, Kilgo, Kregel, & Lazzari, 1993; Solomon, 1995; Teplin, et al., 1993) However, the emphasis placed on the importance of a multidisciplinary team for early intervention by Part H of IDEA stimulated interest on improving this situation (e.g., Blackman, Healy, & Ruppert, 1992; Coury, 1990; Peter, 1992; Schwab, 1991).

The American Academy of Pediatrics (AAP) has been active in the development of comprehensive medical education programs to meet the needs of pediatricians in practice. In 1978 a specialty task force released a report on pediatric education. This task force assessed the health needs of children with disabilities and the educational needs of the pediatricians who assess the children. Among the conclusions of the task force were that 1) all pediatricians should have the skills to cope with biosocial and developmental problems; and 2) residency programs need to emphasize training in the provision of care to children with chronic handicapping conditions (The Task Force on Pediatric Education, 1978). That same year the Office of Special Education and Rehabilitation Services of the U.S. Department of Education funded the AAP to develop an inservice training curriculum that was used with over 5,000 primary care physicians who serve children with disabilities (Powers & Healy, 1982). Since then, however, there have been few programs which have had the scope and effort of this program (Coury, 1990).

The AAP has continued to develop other training materials for use with physicians and others involved with service for children with disabilities. For example, Project BRIDGE was developed for interdisciplinary teams providing early intervention services to children aged birth to three and their families (Spencer & Coye, 1988). This program provided inservice training to physicians in the context of a broader interdisciplinary focus. Most recently, the AAP published guidelines to support the role of the pediatrician in the development and implementation of IEPs and IFSPs (Committee on Children with Disabilities, 1992). This statement from the AAP Committee on Children with Disabilities was reaffirmed in an update published in 1999.

In an effort to expand a physician's knowledge base on children with disabilities from a **preservice** perspective, a number of initiatives have been implemented by medical schools around the country. For example, there are a number of fellowship (post residency) programs in developmental pediatrics. There are also an increasing number of medical schools that are implementing curriculum on children with disabilities at the residency training level. In the past, most programs, such as those at Ohio State, the University of Minnesota, and the University of Connecticut, provided a one block month rotation for residents focused on children with disabilities and chronic illness. Some type of structured curriculum was usually used by these programs (e.g., Guralnick, Richardson, & Heiser, 1982). Other programs, such as those at Michigan State University, the University of Vermont, the University of New Hampshire and the University of Maryland have expanded these experiences to include a long term relationship with a family with a child with disabilities during the entire residency period. Again, these programs have been relatively unique. However, there has been encouragement to expand these types of experiences into a longitudinal curricula (Brewer, et al., 1989).

Other recommendations for residency education have centered around providing education to pediatricians to enable them to provide a "medical home" for the primary medical care of each child (Koop, 1987). This home should be comprehensive, coordinated, family-centered, and community-based. This concept has been endorsed by the AAP and the Bureau of Maternal and Child Health (National Center for Networking Community-Based Services, 1989). In order to provide the training necessary to ensure the implementation of this model of medical care, training activities must be available. In Hawaii, for example, the State Health Department has been providing a variety of activities for pediatricians (Peter, 1992). These activities have been supported by both the agency for Part H/Part C services and the state chapter of the AAP.

Historically, there have been a number of barriers to expanding the scope of medical education and, in particular, residency training, for pediatricians. Among them are the cost of the additional training time and the already over crowded nature of the pediatric residency curriculum (Teplin, et al., 1993). The Association of American Medical Colleges has hypothesized that there may be a number of additional factors affecting the slow nature of change within medical school curricula. These include the traditional conservative attitudes of medical educators, system ambiguities in authority and structure for changing the curricula, and the relatively low status given to education at larger medical centers where greater emphasis is placed on medical research and clinical care. Continuing education activities have an additional barrier because of their voluntary status. That is, in some states such as Connecticut, there are no state requirements for continuing medical education for practicing physicians (including pediatricians), therefore necessitating a strong residency curriculum.

Connecticut Status on the Involvement of Physicians in Early Intervention and Special Education: Prior Evidence of Need for this Project. Connecticut passed (May 7, 1996) legislation (Public Act 96-185) which was signed into law on June 6, 1996, to continue participation in Part H of the Individuals with Disabilities Act (IDEA). This legislation changed the Part H lead agency in Connecticut from Education to Mental Retardation (DMR) (see following section for more information on Part H). A unique component of the legislation was the requirement that **"The IFSP shall be developed in consultation with the child's pediatrician or primary care physician"** (CT P.A. 96-185-3c). Early intervention programs (N=32 private programs, plus DMR as 33) had to coordinate the IFSP with physicians beginning July 1, 1996.

Special education services are provided by 169 town school districts (local education agencies). These school districts operate independently, though there are six Regional Educational Service Centers that provide a variety of functions for school districts, including some special education services.

The Department of Health Services provides a variety of services to children with disabilities and special health care needs. The state provides health services to infants and children through 833 private pediatricians' offices, 10 community health clinics, and 92 community based well baby clinics. In addition, child development services are provided through 24 clinics statewide. A small number of school districts (N=12) also have school based health clinics.

Prior to this project, two surveys were conducted with Connecticut pediatricians about their role in early intervention and special education. These surveys were sent by the project director of this grant in conjunction with the Connecticut Chapter of the American Academy of Pediatricians (AAP). The first survey was a mail questionnaire sent in 1993. The purpose of this survey was to assess the then current knowledge base, and involvement of pediatricians with both the early intervention and special education systems, and the other public programs that serve children with disabilities. The study addressed the following areas: 1) The pediatricians' background and current practice; 2) The pediatricians' knowledge of, and experience with children with disabilities; 3) The pediatricians' understanding of public programs and their relationship to the care of children with disabilities; and 4) The pediatricians' interest in more information and training on children with disabilities, and what type of training would best assist them.

Three hundred eleven (of 777) pediatricians or 42.9% of the sample returned the questionnaire. The results demonstrated that most pediatricians were uninformed about IDEA, as well as other public programs that serve children with disabilities and their families. This is not surprising since this sample also reported a lack of training regarding children with disabilities within their medical school and residency training programs. These data supported similar findings by others also interested in the involvement of physicians with children with disabilities (Dworkin, Shonkoff, & Leviton, 1979; Scott, et al., 1993).

While a lack of knowledge on programs for children with disabilities was well documented on this sample, two areas were worth noting. First, most of the responding pediatricians reported that they considered themselves as service coordinators for the children with disabilities in their practice. However, few reported having heard of the role of a service coordinator under Part H of IDEA. This lack of knowledge about the Part H program obviously limits the pediatrician's ability to provide comprehensive service coordination services to the children in his/her practice who have disabilities. Secondly, although most of the respondents accepted Medicaid patients, less than half reported that they performed EPSDT checkups. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program is part of the Medicaid program for children, and as such, was initiated in the late 1960's. EPSDT mandates early and periodic medical, dental, vision and developmental screening, diagnosis and treatment of all children and youth under 21 years of age who are Medicaid eligible. EPSDT can be an important component of early intervention and special education child find.

One of the survey's most significant findings was the large number of physicians interested in learning more about subjects pertaining to young children with disabilities and services under Part

H and Part B of IDEA. The results of this survey strongly supported a need for increased information and training to improve the pediatricians' ability to provide more comprehensive care to children with disabilities.

A second survey was conducted by phone interview to 200 physicians of children enrolled in the statewide early intervention system. This survey was designed to assess the physician's involvement with the child's early intervention plan. The interview contained specific questions about the child, as well as general questions about the provider's experience with the early intervention system. Of the 200 interviews conducted, 46% of the respondents had never heard the term IFSP, and 69% had never been involved in the development and implementation of a child's IFSP. Of the 46 providers who were involved in the IFSP, the majority (83%) participated through communication with the parents. All 46 were asked how they would prefer to be involved with the child's early intervention. The majority (76%) preferred a telephone call from the service coordinator, and 32% wanted to be able to provide information via a health concerns or care record. Many suggestions about the early intervention system were collected through these interviews. **The most important outcome of the survey results was the inclusion of the physician in the IFSP process as required by Connecticut's Part H legislation.**

In 1992, the project director (of this personnel preparation program) was awarded a special projects personnel preparation project to plan, develop, implement and evaluate training materials and activities for medical students, pediatric residents, and practicing physicians (pediatricians, family practitioners) on early intervention and special education. The project had four objectives: 1) to develop self-study manuals for medical students, pediatric residents and practicing physicians on content related to the physicians' role in early intervention; 2) to implement training activities for medical students on the physicians' role in early intervention (and special education) at the University of Connecticut School of Medicine during their involvement in their Introduction to Clinical Medicine course; 3) to implement training activities (12 hours) for pediatric residents on the physicians' role in early intervention (and special education) at the University of Connecticut School of Medicine during an **elective** rotation (one block month) on the child with chronic illness and disability; and 4) to implement training activities for practicing physicians on their role within early intervention in Connecticut through Grand Rounds presentations at Connecticut's hospitals and in the community. **A major focus of this project was to improve the coordination of services among health, early intervention, and educational agencies within communities in regard to services for infants, and children with disabilities and their families.** The results of this training project led to the application for this grant.

Another result of the above mentioned project was that the UConn Pediatric Residency Program instituted a new curriculum organization on July 1, 1996. This curriculum is presented on Table 1. Each box represents a four week block. However, the ambulatory care blocks are implemented throughout the year. Each resident has one block off a year. As a result of the success of the Special Projects Grant, Component 2 of this grant was proposed and funded, and all residents proceeded to complete a unique, longitudinal, (three year) rotation with children with disabilities. The rotation consisted of a continuity experience during ambulatory pediatric blocks in which four half days a month were focused in the development of competencies related to enhancing early intervention and special education for children with disabilities. The four half days a month consisted of one learning activity from a module on topics chosen to enhance the resident's involvement in early intervention and special education and three clinical experiences with a child with a disability in their own continuity clinic or a specialty clinic.

This project supported the development of materials and experiences related to the pediatrician's role in the provision and support of early intervention and special education. **This was the first such longitudinal requirement implemented in the country.** All UConn pediatric residents (N=92) were required to complete the competencies and experiences planned for this rotation. As a result children, families and early intervention and special education programs have benefited from their participation during the training program and are continuing to benefit after the residents graduate and go into practice around the state, and around the country. Additionally, the project director and co-director expanded the project's impact by presenting an overview of the project at annual pediatric professional meetings around the country. The project also assisted other medical schools who showed interest in developing such an experience, by disseminating information when inquiries were received. This was facilitated by the new Educational Guidelines for Residency Training in General Pediatrics (Ambulatory Pediatric Association, 1996) which allowed for such a longitudinal experience within its framework of competency based training. These guidelines include the training requirements of the Residency Review Committee (RRC) of the Accreditation Council for Graduate Medical Education. They have also been approved by the AAP.

Table 1: Pediatric Residency Program at UConn Beginning 7/1/96

UNIVERSITY OF CONNECTICUT SCHOOL OF MEDICINE PEDIATRIC RESIDENCY PROGRAM			
Rotation Experience *	**PL-1st Year**	**PL-2nd Year**	**PL-3rd Year**
1	CCMC Inpatient	Ambulatory Pediatrics **	CCMC Senior Supervisor
2	CCMC Inpatient	Ambulatory Pediatrics	CCMC Senior Supervisor
3	CCMC Inpatient	Ambulatory Pediatrics	Ambulatory Pediatrics**
4	CCMC Inpatient	Ambulatory Pediatrics	Ambulatory Pediatrics**
5	Pediatric Emergency	Behavioral & Developmental Pediatrics	Ambulatory Pediatrics**
6	Ambulatory Pediatrics **	Adolescent Medicine	Ambulatory Pediatrics**
7	Ambulatory Pediatrics	Pediatric Emergency	Critical Care - NICU
8	Ambulatory Pediatrics	Critical Care - PICU	Critical Care - PICU
9	Ambulatory Pediatrics	Critical Care - NICU	Pediatric Emergency
10	Ambulatory Pediatrics	Elective	Pediatric Surgery
11	Critical Care - PICU	Elective	Elective
12	Critical Care - NICU	Elective	Elective
13	Critical Care - NICU	Elective	Elective

* This chart does not represent the sequence of rotation experiences for any one resident. It represents the number and type of experience in which each resident was involved.

** The Children with Disabilities experience was integrated into the Ambulatory Pediatric rotation which was a continuity clinic experience.

Training Model Description

COMPONENT 2: PEDIATRIC RESIDENTS

The "Children with Disabilities" curriculum was embedded within the three year pediatric residency program at the University of Connecticut and Connecticut Children's Medical Center (CCMC). All residents were required to complete the curriculum. The curriculum was competency based, and individualized for each resident. In addition we utilized the literature on adult learning to guide the implementation of the curriculum (Knowles, 1978; 1980). The competencies for the curriculum included those applicable to the rotation as contained in the educational guidelines approved by the Accreditation Council for Graduate Medical Education. The content, methodology and clinical experiences for this component are in Figure 1 and described as follows.

Content. The content of the program was derived from the literature, as well as areas of competencies identified by residents who completed the one month elective block rotation on children with disabilities previously directed by the project director. In addition, the key personnel of this project refined and approved the content areas.

Each area was presented as an independent module. Each module had a manual to accompany it that contained background information, objectives, competencies, references, and additional learning experiences. Through the three years the content was cumulative, although year 1 focused on the family, year 2 on the team, and year 3 on the system.

Methods. A variety of planned experiences were used to deliver the curriculum content. They included presentations of content by project faculty and others. Each module began with a didactic presentation/discussion outlining expectations for the module and introducing the subject matter. Each resident then progressed through the competencies assigned in the module and proceeded to the next module. For example, the first didactic on family centered care might have included viewing a video and talking with two parents of children with disabilities in the family center. A session on teaming may have included a video on team process and meeting professionals from other disciplines. Home and program visits were implemented so that the resident could gather information specific to the early intervention/special education and related service needs of a child. Likewise the residents visited various early intervention and special education sites, including those linked with children they had in their clinical practices, and whom they visited in the home. Third, the resident might observe, then participate in an IFSP and an IEP team meeting for children in their clinical practices. Fourth, the resident might be responsible for developing a longitudinal coordinated care plan for health related services in an IFSP or an IEP for the children seen in their continuity practice. Fifth, the resident observed and participated in state and local policy and advisory boards for early intervention and special education. These experiences were **supervised** by project faculty. The supervision consisted of orientation, planning, documentation, evaluating and debriefing. A procedural manual and forms were used to delineate these procedures. Lastly, the students attended a periodic evening seminar of two hours. Initially, the seminars were to be specific to the year of the resident (PL1, PL2, PL3) and focus on the content delineated for each year (1 - family; 2 - teams, 3- systems). However, for various reasons, including the rigors of the resident's work schedule, this proved to be too cumbersome, and a more generalized approach to the seminars was developed. Each seminar focused on a topic of the resident's choosing. These topics ranged from "How to give bad news" to "pediatric mental health" and others. This was a much more popular approach to the seminars and, in keeping with adult learning theory, ensured better attendance and participation from the residents. Each seminar had least one guest speaker and at least one

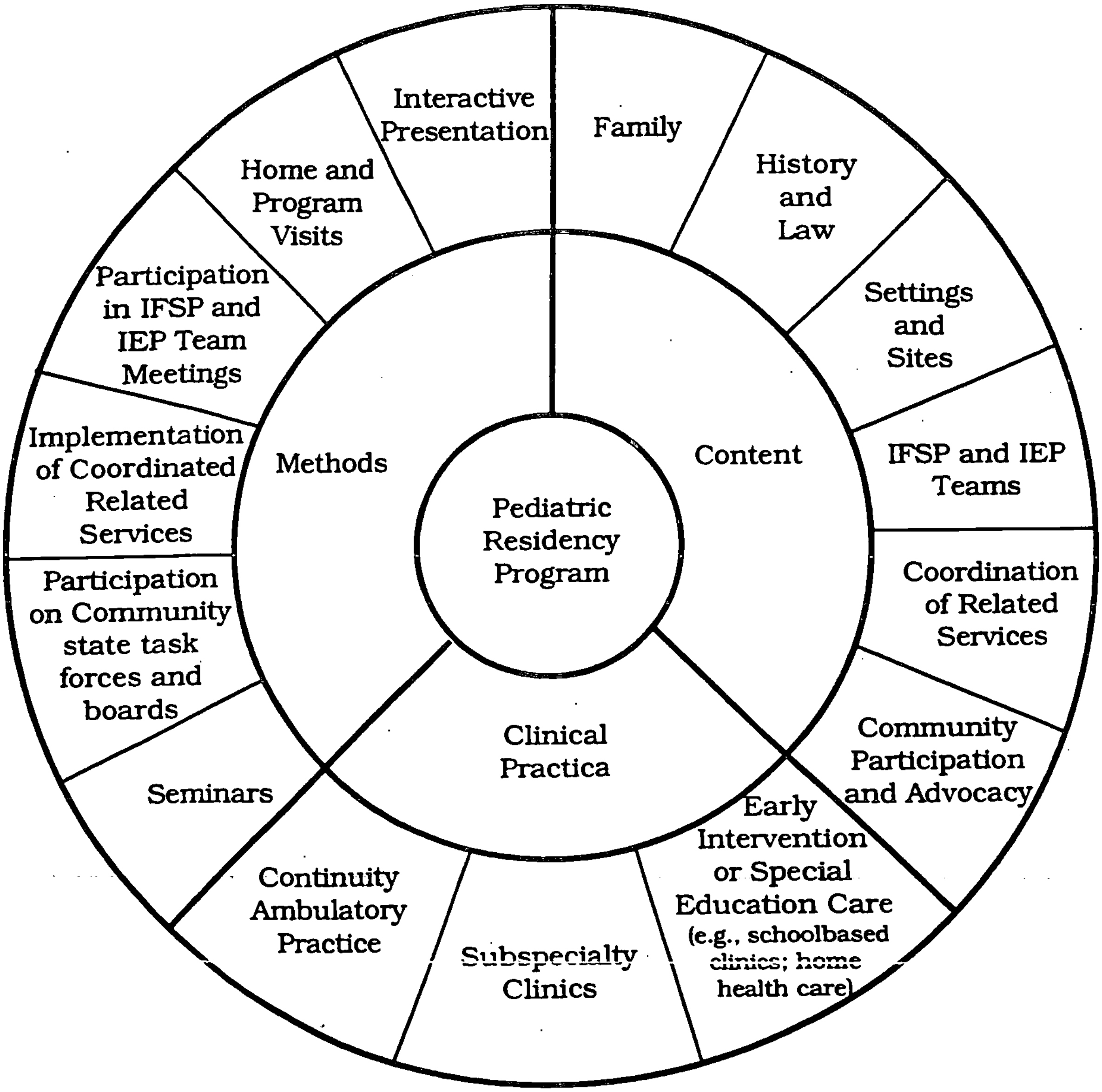

Figure 1
Pediatric Residency Program Overview

resident presenter, as well as discussion on the topic. The residents received a stipend for attendance because the seminars took place outside their work day (and paid residency requirements).

Clinical Experiences. The residents were required to participate in the clinical care of children with disabilities at CCMC or other ambulatory sites. Each was required to identify a child with a disability in their continuity clinic. This clinic met at least one day per week at a clinical practice site over the three years. During the three years, the resident provided care to their own patient group under the supervision of an attending physician. The residents were also required to participate in specialty clinics at CCMC. These clinics include those for children with muscle diseases, cerebral palsy, spina bifida, complex medical needs, neurological diseases, genetics, NICU follow-up needs, etc. The resident was required to gather information and provide input to the family, and to the early intervention/special education program that the child attended, on the health related issues that impacted the child's learning needs. This link occurred through the methodology previously described. Evaluation occurred by observations and contact logs.

A detailed explanation of the procedures follows with the description of progress during the three years within each project objective.

Objective 1.0 Develop a preservice personnel preparation program

Activity 1.1 Assess training needs.

All residents were informally assessed on their need for training relevant to their particular interests, experience and expectations for the future. Orientation to the Children With Disabilities Rotation was provided for each new resident beginning the program. At this time, their experience with children with special needs was reviewed and their interests divulged. During year 2 of the project, a questionnaire was devised (please see Appendix C for a copy of this form) to determine each resident's previous experience with children with disabilities and their families. The questions were all aimed at different themes in this curriculum, for example, we not only asked about the resident's general experience with disability but also about his/her experience on teams and in the advocacy realm. This background information was not only used by the Project Coordinator to help develop appropriate experiences but also by the Medical Consultant during biannual debriefing sessions. This information gave the Medical Consultant a baseline of experience for the resident. They then looked together to see how this curriculum could increase the resident's knowledge and experience.

Meetings were held with each third year resident, at the beginning of the year, to develop a plan for the rest of the upcoming year according to their interests. Residents sometimes entered and exited the program at unusual points in time. For example, in year 2, three new third year residents began the program. All three had been through two years of residency in different programs. Two of them were only here for one year. We personalized each of their year rotations to fit the experiences they wanted and needed (based on their past experience and knowledge of the material). The third resident was here for a total of 2 years. She followed the entire first year of the curriculum sequentially and then we developed a plan for her last year.

Activity 1.2 Convene Advisory Board.

The Advisory Board was made up of the Director and Coordinator of the Project and 3-5 pediatric residents. The residents were asked to volunteer to sit on this board for one year. There was at least one resident from each year of the program sitting on the advisory board at any one time. The advisory board met twice during the project to receive input from the residents, and to discuss topics for the evening seminar series. In the final year of the project it was felt that a meeting of the board was not necessary, as we had devised other methods of feedback and input from the residents.

Activity 1.3 Meet with project consultant.

Dr. Sally Rosengren resigned from the Medical Project Consultant position in year 2 of the project. Dr. Eileen Fisk joined the project as Medical Consultant in June 1999, in a half-time position. This was a significant increase in the time devoted to the Medical Consultant's position, which allowed for more on-going support for the residents and Project Coordinator (see appendix D for the Medical Consultant's Job Description). Dr. Mark Greenstein continued to conduct biannual debriefing sessions with the residents until September 1999, when they were suspended. Until Dr. Fisk joined the project, the Project Coordinator met with Dr. Greenstein in person approximately once a month, and discussed the then current issues via telephone approximately three times a week. The Project Director, Project Coordinator, and Medical Consultant met once every other month. Once Dr. Fisk joined the project, she was in daily contact with the Project Coordinator, either in person, or by telephone. From this point on the Medical Consultant and Project Director also were in frequent contact, either in person, or by telephone.

Activity 1.4 Refine curriculum content.

The entire curriculum was refined for content during year 3. Each module was in need of being updated since the Reauthorization of Individuals With Disabilities Education Act. Each module was reviewed by the Project Coordinator and Medical Consultant for possible changes in content and format. The module was then given to the administrative staff to input changes, and finally, the module was given to the Project Director for review. The resource allocation section of the Interagency Collaboration, Service Integration, and Resource Allocation module was updated by Ms. Molly Cole. Ms. Cole is the Director of the Family Center at Connecticut Children's Medical Center and an expert on such issues as insurance and resources. Ms. Judy Blei, the lobbyist for the Connecticut Chapter of the American Academy of Pediatrics, assisted us in updating The Legislative Process section of module seven, including the evaluation forms. In addition to being updated for content, some modules were combined, some community visits were eliminated because of duplication, and time was slotted for making up missed visits secondary to illness or weather problems. All this occurred in response to feedback from the residents themselves regarding the project. The modules that were combined were: numbers 5 and 6, Communication Skills and Team Process, and Team Participation and Facilitation Skills; and numbers 8 and 9, The Legislative Process, and Advocacy and Responsibility. The newly combined modules are: number 5, Communication Skills and

Team Participation; and number 7, Advocacy and Responsibility and the Legislative Process. Thus, the project now had 7 modules spanning the 3 years of the curriculum instead of 9.

Some duplicated community visits were eliminated in old modules 2, 3, 5, and 6. Slots were allocated for make-up sessions (missed for weather or illness) in new modules 2, 5, and 6. Some modules grew from 4 or 5 components to 6 or 7 components. For instance, the advocacy project in the new module 7 was allocated additional time and grew from 2, one-half day slots to 3, one-half day slots. We also changed the name of the Learning Activity Schedule to Rotation Schedule, to be more in keeping with the resident's usual curriculum terminology. The curriculum changes over the course of the 3 years reflected accepted changes in best practice and the law thus it always took priority and was constantly a work in progress.

In year 2 of the project additional articles from the Academy of Pediatrics were added to the appendices of the curriculum. Child and Family Studies obtained approval to copy and distribute these articles. Also in year 2, special guidelines and evaluation forms were developed for The Hospital For Special Care Specialty Clinic Visit and Adaptive Equipment Specialty Clinic Visit. Child and Family Studies obtained approval to include three articles from the journal Pediatrics, as an addendum to the Hospital For Special Care Specialty Clinic Visit. An addendum was also included with the Adaptive Equipment Specialty Clinic forms summarizing the specific disabilities of the children who attend this clinic. Permission was granted for five articles to be included as appendices to the NICU Follow-Up Specialty Clinic visit. Please refer to Appendix E for all of these additions.

Evaluation and preceptor forms were modified a number of times over the course of the project, to more accurately signify if the residents were observing and applying the knowledge that they learned in the didactic sessions. Resident self-evaluations were a combination of yes/no questions and open-ended questions. The open-ended questions were meant to urge the resident to reflect back on the new material he/she learned and signify if what they were observing was best practice. In addition, some of the open-ended questions pressed the resident to apply the material they had learned to the situation they were observing. The preceptor forms were changed to all yes/no questions to simplify the form. An additional preceptor form was added to each module for component one, the didactic session. This form was completed by the facilitator of the session. It included such ratings of reliability, participation, and understanding. This form was used starting May 1, 1999. In addition to changing the evaluation and preceptor forms, the Pre and Post-Tests were also changed to accommodate concerns from the residents regarding the amount of time consumed to answer open-ended questions. This concern was raised in light of the resident's already heavily loaded schedule and long work week. During the year 3 curriculum restructuring, instead of open-ended questions to test the resident's knowledge, the Pre and Post Tests were changed to question the resident's comfort level with the concepts introduced with each new module. The comfort level was measured on a Likart Scale of 1-5. This change was welcomed by the residents as time-saving and relevant, yet it continued to give the project a tool to measure the resident's progress as they began and finished each module. Please see Appendix F for an example of the evaluation forms in the Family Centered Care module.

The Orientation Manual (appendix G) has also been refined over the course of the project. This manual was reviewed with and given to each new resident that entered the rotation. In the second year of the project the manual was updated to include a section on the resident's "Individual Portfolio", distinguishing it from the resident's "Progress File." The resident compiled their own individual portfolio over the three years, including different types of material gathered from different visits or experiences that were important to them. Please see the manual for details. The Individual Portfolio was under review in year 2 of the project because it was thought not to have been developed by any resident who had been debriefed up until that time; however, subsequent questioning of the residents disclosed that they were indeed gathering information from interactions throughout the curriculum and filing it for later use. This fulfills the description of a portfolio as we designed it in the proposal, even though the residents did not use the specific term themselves. A progress file on each resident was kept at the Division of Child and Family Studies and included his or her self-evaluations, preceptor evaluations, evaluation forms, and biannual debriefing transcriptions.

Also included in the orientation manual as of year 2, was the requirement for a "Biannual Debriefing." Each resident was debriefed biannually by the Medical Consultant. The Medical Consultant debriefed six to eight residents a block (4 week period of time). For the residents based at the Connecticut Children's Medical Center, the Medical Consultant discussed the schedule with the chief resident and pulled the residents from the primary care clinic for, approximately, 45 minutes to 1½ hours. For the residents based at the Burgdorf Health Clinic and the Saint Francis Hospital, the Medical Consultant planned their visits on Friday afternoons, after a mandatory meeting for them. If needed, the Medical Consultant could also debrief one to two residents during their child development blocks. The time to debrief the residents was never formally figured into the schedules of the residents. This biannual debriefing plan was developed in the second year of the project, but due to the time constraints of residency and limitations in the primary care clinic, it did not work smoothly and was dropped from the project in September, 1999.

Due to the change in Medical Consultant and thus, a change in debriefing style, the debriefing forms were no longer used after Dr. Rosengren resigned from the project. Dr. Greenstein chose to use outlines of the modules and information from the resident's progress file. He revolved each session around (1) getting feedback on the rotation, (2) finding out if the resident was applying the information, and (3) reviewing the progress file and evaluation form (please see Appendix H for a sample evaluation form, and for a breakdown of the information sought in debriefing sessions). The sessions were audio taped and then transcribed. The transcriptions were coded by the Project Coordinator and used as qualitative data. There are 18 debriefing transcriptions coded and put into a summary format. Please refer to Appendix I for the debriefing summary, "An Exploration of Attitudes, Experiences, and Feedback."

In addition, a description of the evaluation of the resident has been added to the orientation manual. A review of each resident was completed by the Project Coordinator in years 1 and 2, and by the Project Coordinator and Medical Consultant in year 3. An evaluation form (Appendix H) was created for this purpose. The Project Coordinator rated the resident based on preceptor ratings and her interactions with the resident (i.e., flexibility). A copy of the evaluation was given to the resident, a copy was then stored in the resident's progress file at Child and Family Studies and another copy placed in their file at Connecticut Children's Medical Center.

Please see Activity 1.6 of this report for the refinement of competencies within the curriculum.

Activity 1.5 Refine methodology.

Refinement of the methodology has been ongoing. The final method of presenting the information and evaluating the effectiveness of the curriculum was as follows:

Method of presentation: Each module included a Table of Contents, Introduction, Organization of the Module, Objectives, and Components one through four, five, six or seven, as appropriate. Component one always began with an Outline of Content, Related Readings, Related Videos, and a Family Study (with discussion questions). Due to the resident's requesting a more interactive didactic session, the required viewing of videos was dropped, and they became an optional component; therefore, a new section was created for the module called, "Related Videos." This section listed the videos that could be incorporated into the session if desired, or could be viewed at other times if the resident requested additional information on a particular subject. The related readings were added to the modules to increase the resident's motivation to further investigate the topics and point them in the right direction. The related readings were updated in year 3 of the project, ensuring that current best practice was represented. Each component, including one, began with the Location and Times, Format, and Resident's Responsibilities. Component one concluded with a revisit to the Family Study, which included answers to the discussion questions and a resolution. There was always a

Satisfaction with the Session Presentation and a Performance Rating by Preceptor completed for each didactic session. Components two through three, four or five (community visits) included Guidelines for the community visit and all of the relevant evaluation forms, including the self-evaluation and preceptor evaluation forms. The module then included the Reference page and a Satisfaction With Module Presentation form. There were appendices in most of the modules, but they were limited; the Pre Post Test was always the last appendix. Please refer to Appendix F for an example of a complete module.

Component one was always a training session on the didactic material, providing the foundation information in regard to the particular topics. These sessions were facilitated by the Project Coordinator and/or the Medical Consultant and included the resident and an appropriate staff member from the Division of Child and Family Studies. At times, certain trained staff members conducted these sessions without the Project Coordinator. In the third year of the project we were more successful at scheduling a number of residents for each didactic session, rather than a single resident. This had been an on-going complaint from the residents that was resolved through diligent cooperation from the Chief Residents, who were responsible for putting together a very complex overall schedule. Also due to resident request, many more examples of application of the material were added to the session. These sessions developed to become interactive between the staff and the resident. The project staff facilitated the residents applying the knowledge to their own experiences during the session, making the information relevant to their particular practice. Efforts were made to include a parent of a child with a disability at each didactic session. This not only gave the resident another case study to apply the information to, but also gave them the parent's perspective on the information. The resident could then ask questions and get immediate feedback on how a family could be impacted by and deal with certain situations. During the Family Centered Care Module, a panel of families was present to discuss how family centered care had impacted them. In year 1, a preliminary packet was produced to help in training parents who participated in the didactic sessions. In year 3 we developed a full parent training manual to aid in the orientation of parents participating in the project.

It was possible for the students from component 3 of this grant to assist the Project Coordinator in relaying the information and giving pertinent examples to fulfill certain competencies in their program. The didactic sessions in which these students could successfully fulfill competencies were, (1) Early Intervention, (2) Team Based Service Models: the Role of Other Professionals and (3) The Legislative Process.

Components Two through Three, Four or Five of each module were practicum experiences in the field. These experiences promoted the application of the principles learned in Component One. Each of these components was organized in an identical manner: Guidelines for Practicum Experience, Resident's Self-evaluation, and Performance Rating by the Preceptor. Project staff accompanied the resident on some of the visits, but not all. Project staff did not attend the specialty clinic visits at Connecticut Children's Medical Center with the residents, but every visit had an assigned preceptor who briefed and debriefed the resident. Outreach to the clinics continued throughout the project. Social Workers in each of the specialty clinics initially acted as preceptors to the residents. Due to a cut back in staffing at the Medical Center, the social workers were removed from many of the clinics. The Project Coordinator identified other individuals in these clinics to be preceptors for these visits (i.e., nurse practitioners). Please see Activity 1.7 for a listing of all of the specialty clinics involved in this program. The Project Coordinator kept in close contact with the Manager of Family Support, who supervised the social workers (please see Appendix J for sample meeting records).

Method of Evaluation: There were many methods used for evaluation. The pre-test was given prior to the didactic session. Directly following the didactic session, the session satisfaction was completed by each resident. Beginning May 1, 1999, a preceptor form was also completed after each session. The resident then attended his/her practicum experiences, completing the self-evaluation for each and giving the preceptor the performance rating to complete. In the second year of the project we combined the previous Resident Reflective Evaluation form with the Resident Self-evaluation form, and it then existed only as the Resident Self-evaluation form. This change occurred mainly because the residents felt that the paperwork was overwhelming. We also added a Preceptor Form B for the visits that the resident attends with their continuity patient. This included, for example, the visit to this patient's home or the visit to this patient's school. An example of this form is in Component two of the Family Centered Care module in Appendix F. The Project Coordinator frequently reminded the residents to give the preceptor forms to the preceptor. The resident was also told in advance exactly who the preceptor was at each site, so there was no confusion.

Residents could take the post-test at any point after the didactic session, but most of them took it as each module was completed. When all of the components in the module were complete, the resident filled out the module satisfaction survey and moved on to the next module. At times a resident moved onto a new didactic session, without finishing a module, if scheduling conflicts occurred (rather than missing a visit altogether).

Lastly, the resident was debriefed biannually by the Medical Consultant, as discussed previously. Please see Appendix H for a copy of the evaluation form. All the debriefing dates were tracked on a chart that was kept and maintained by the Project Coordinator.

Activity 1.6 Refine competencies.

Over the course of the 3 years, in keeping with best practice, the competencies were occasionally changed based on the needs and interests of the adult learners. Each competency took place during a scheduled one half day (4 hours) of the resident's ambulatory blocks for three years. Internal Medicine/Pediatric (med/peds) residents spread these visits over four years. In the second year of the project Physician Level 1 (PL 1) residents were given a choice of keeping a journal reporting how and why they were advocating for families. The benefit to keeping a journal was to (1) keep track or their own advocacy efforts so that their advocacy project (in the 3rd year of the curriculum) could draw upon their past experiences, and/or (2) record different issues that arose and then check for patterns or recurring themes. These patterns could direct their focus on certain issues for system changes for their advocacy project. Residents then, would have specific examples and details over time. As this was not a requirement, it is unclear exactly how many residents chose this option. An advocacy project had been an elective component until the final year, and, as such, only 2 residents completed advocacy projects prior to this. During the final year we made completion of an advocacy project a requirement for those senior residents who were graduating. All 13 residents who graduated from the UCONN Residency Program in Pediatrics in the year 2000 (and who advanced along the typical 3 year residency program time line) completed an advocacy project for this program. Over the course of the program, these projects ranged from surveying the entire US pediatric residency programs on training in advocacy, to simply researching available resources for children with disabilities in other states. These other states were always the state in which the graduating resident was going to be practicing. These projects will be further addressed in the impact section of this report, and a listing of the advocacy projects themselves can be found in appendix K.

The Legislative Process competencies have essentially remained the same. Ms.Judy Blei, the Lobbyist for the Connecticut Chapter of the American Academy of Pediatrics, was contracted to precept residents during these visits. Residents visited the Capitol and the Legislative Office Building to observe public hearings, task forces, advisory councils, committee meetings, the house in session, etc. and meet with legislators. A great advantage to conducting these visits with Ms. Blei and her staff was that the resident was given a great deal of background knowledge on the issues and the process during the visit. With Ms. Blei they were able to meet people, such as legislators, that they would not have had in the past. Please see Appendix L for two examples of a ½ day spent with Ms. Blei and her staff. These examples actually happened. Also in this Appendix are meeting records. Ms. Blei and the Project Coordinator communicated using e-mail, telephones, and beepers.

Activity 1.7 <u>Organize and schedule clinical practica</u>.

Clinical practica, didactic sessions, and community visits were arranged by the

Project Coordinator. A total of 948 visits have occurred since the program began, with 239 "extra" visits completed. Extra visits were visits that did not fit into a curriculum visit but were relevant to children with disabilities, i.e., a conference on early intervention. In the final year of the project, "extra" visits also included those community activities that were removed from the refined curriculum product, yet had already been completed by residents who had transitioned through those particular modules prior to the refinement. The schedule of each resident was reviewed individually and appropriate competencies were planned. Schedules tended to be inflexible, although, if given enough advance warning, a resident could be scheduled for a certain day by the Chiefs. Particular specialty clinics fell on certain days of the week only. Residents could request to attend these clinics with advance notice.

Each resident scheduled for Children With Disabilities Rotation in a given block received a calendar with his/her planned experiences. Each resident also received a breakdown of his/her visit a few days in advance of the visit. The resident's experiences follow the list of competencies in sequence as much as possible. The Project Coordinator gave a copy of the block schedule to the Chief Residents and the Primary Care Clinic (PCC) Attending Physicians prior to each block. We did this to help alleviate the challenges we had getting resident's out of the PCC on time to make their Children With Disabilities Rotation visit.

We instituted a plan of action for alleviating problems that arose for residents regarding community visits, in the event that the Project Coordinator was unable to address the issue (due to illness or on vacation and thus unavailable). The Project Coordinator had backup staff to address the problems and make decisions. An example of a problem would be if a resident called into the front office and did not know where they were to go that day for their visit. The front office staff then had directions on what steps to take when a problem arose and the Project Coordinator was not available.

Scheduling the residents consumed a great deal of the Project Coordinator's time, and the possibility of computer scheduling was investigated. A consultant was contacted to help determine if there was software that existed that could be used or modified for use. It was determined that no software in existence would work and a scheduling program would have to be produced. At that time, a computer consultant firm, DeSai Systems, was asked to give a proposal, including cost, to produce such a computer program and the amount of time it would take. The meeting records and proposal are in Appendix M. The proposal of time was reasonable but the amount of money was significantly higher than what this grant funded program could pay. The offer was declined. The Project Coordinator and various staff from Child and Family Studies continued to search for a scheduling program, but none was found.

Outreach into the community to develop placements for the resident's was ongoing (see Table 1 for information on outreach and Appendix J for sample meeting records). In year 2 we opened up more specialty clinics to residents and more special education programs. A letter and brief description of the program was sent to particular school systems in the area in August 1998. The Project Coordinator followed up on these letters with phone calls to the Directors of Special Services in each school system. This arrangement worked well in that the program found new school systems to utilize. Outreach continued into the third year, with a focus on early intervention programs, both natural group environments and home based. A list of placements that worked with this program follows:

- Specialty Clinics: Genetics, Muscle Disease, Muscle Respiratory, General Pulmonary, Bronchial Pulmonary Dysplasia, Cystic Fibrosis, Myelomeningocele, Diabetes, Craniofacial, NICU Follow-Up, Children with Special Health Care Needs, Hospital for Special Care, Rehabilitation-Adaptive Equipment, Neurosurgery, Orthopedics, Hematology and Oncology, Cerebral Palsy, Cardiology, and Neurology.

  Many of the clinics above had been in the program to begin with but then were not utilized for some time because of the reorganization of the hospital staff. The social workers were the contact and the preceptors for most of the clinics. When they were removed from the clinic teams, the program lost their contact. The Project Coordinator made new contacts in the clinics and resumed these visits. Residents also attended clinics with families that work for Child and Family Studies that have children with special needs. In these cases, the parent was the preceptor. Contact was made to the Family Support Department at Connecticut Children's Medical Center to continue the dialogue between the Project Coordinator and the social workers. These social workers were not only involved in the specialty clinic visits, but also in discharge meetings. The communication between the Manager of Family Support and the Project Coordinator was ongoing.

- Family Home Visits and Family Panels for Family Centered Care Didactic Session: 16 families were involved in home visits (Appendix N). These parents, plus parents who work at Child and Family Studies, could be involved in family panels. Parents were asked to come to Connecticut Children's Medical Center for Family Panels on Family Centered Care or to the University of Connecticut Health Center for the other didactic sessions. The families who worked at Child and Families Studies were primarily utilized for the other six module didactic sessions.

  Outreach to families was ongoing throughout the project, via flyers, telephone contact and networking. with the Local Interagency Councils, Birth to Three Programs and School Systems. Families were also approached by The Family Center staff. Families that had been involved in other grants or projects showed interest in this grant, and some were recruited by the Project Coordinator. All families who were not from the resident's continuity clinic attended training sessions prior to interacting with the residents. A preliminary parent training packet was created in the first year of the project for these sessions, and this was formalized into a parent training manual in the third year of the project.

- Early Intervention Program Home-Based: Child Development Center, Early Connections, East Hartford Birth to Three, Stepping Stones, and Project Interact.

  Outreach was ongoing throughout the 3 years of the project.

- Early Intervention Programs: Trinity College Community Child Care Center, New Britain YWCA, East Hartford Birth to Three Playgroup, Child Development Center Playgroup, Capitol Child Development Center, Easter Seals Day Care, New Britain General Hospital Child Care Center.

  Some Early Intervention programs were closed to residents in the second year of the program because they had no children with special needs enrolled at that time. Among these programs were: First Church Nursery School Day Care, Kinsella Daycare, Women's League Day Care, University of Connecticut Day Care Contact continued with these programs to check on enrollment status, but none opened up in the final year of the program.

  Outreach was ongoing throughout the 3 years of the project.

  Connections were made with the CT Birth to Three North Central Program Manager to obtain more natural environments for the early intervention program visit. Other Early Intervention programs were also called, seeking the same information. The staff at these programs had very few suggestions. Infoline was also contacted. Again, they had few suggestions. This particular visit has had the fewest appropriate placements (i.e., natural environments).

- School Systems for Elementary, Middle and High School Visits: Farmington School System, Simsbury School System, Rocky Hill School System, Avon Public School System (elementary only), East Granby School System, Bolton School System, and Canton School System.

  Outreach was ongoing throughout the 3 years of the project.

  South Windsor School system chose not to participate and Bloomfield School System was an inappropriate placement as they had very limited inclusionary placements options for children.

- Advisory Councils: State Interagency Coordinating Council, Local Interagency Coordinating Council (Greater Hartford in particular), The Family Advisory Council, The Family Support Council, The Children's Health Council.

  Outreach was ongoing throughout the 3 years of the project.

- Legislative or Public Hearings: Public hearings randomly came up and could vary. They were offered to the third year residents. For example, The Husky Plan (Connecticut's S-CHIP Program for Health Care for uninsured children), Katie Becket Waiver Agency Hearing and Birth To Three Medicaid Regulations were opportunities given to the residents to fulfill this component. Legislative hearings only occurred when the legislators were in session, approximately from January until June each year. Judy Blei, the Academy of Pediatrics Lobbyist, alerted the Project Coordinator to upcoming legislative events, as well as accompanying residents to legislative hearings.

  Outreach was ongoing throughout the 3years of the project.

Residents were asked to identify a family that had a child with a disability from their primary clinic experience within the hospital (please see Appendix N for a list of the residents and their families). With the family's consent, the resident followed this family through the three years of his/her residency, applying the knowledge he/she gained through this curriculum to support the family. Sixty-two home visits were made to continuity clinic patient's homes. Thirty-six school or early intervention programs, serving continuity clinic patients, were visited by residents. Lastly, seven team meetings were attended by residents, regarding continuity clinic patients.

The Medical Consultant aided the residents in identifying families. The residents were also given "Guidelines for Identifying Children With Disabilities or Special Health Care Needs Within the Continuity Rotation" in the Orientation Manual and the Family Centered Care Module to help them identify a family to follow. Residents were expected to schedule the visits with their special families. If the family spoke primarily Spanish, a translator from The Division of Child and Family Studies helped the resident set up the visit and accompanied him/her to the visit. The resident was given guidelines for working with translators before his/her visit. These guidelines are in Appendix N.

Activity 1.8 Develop training manuals, materials and evaluation instruments.

Over the second and third years, the entire curriculum, including the evaluation materials, underwent edits and refinements (please see Activity 1.4 and 1.5). The curriculum's information sections were updated to reflect both the changes in the law and best practice. After the changes were made the modules were reviewed by the Project Director.

The manuals were developed and edited by the staff at the Division of Child and Family Studies, including the Project Coordinator. Ms. Molly Cole, Director of the Family Center, contributed to the third year of the curriculum and edited the Interagency Collaboration, Service Integration, and Resource Allocation module. Ms. Judy Blei helped to check the accuracy of The Legislative Process information. See Appendix F for a sample copy of a curriculum manual in its entirety.

In addition to the resident orientation manual and curriculum manuals for each module, a family training manual was created in year 3. This acted as a guideline for the parents involved in the didactic sessions, as well as a general reference for the family to consult regarding the project.

A permission slip was created for the resident to utilize when interacting with professionals regarding the child he/she was following for this rotation. Please see Appendix N.

A resident evaluation form was created. This form was completed by the Project Coordinator and/or the Medical Consultant, prior to a debriefing session between the resident and the Medical Consultant. It was then reviewed with the resident at this debriefing session. Please see Appendix H for a copy of the evaluation form.

Thought was given to creating a brochure for the project, but in the end, it was decided that a brochure would not be particularly useful, and the idea was discarded.

Additional materials and experiences, relevant to families and children with disabilities, that further the education of the resident, were distributed to residents on an ongoing basis. For example, residents were invited to a conference on Legislative Advocacy occurring at the capitol in Hartford and a conference given by CATCH on The Husky Plan. Four residents had a chance to be included in the Prader-Willi Syndrome Clinic that occurs only once a year. One resident had a chance to attend the Partners in Policy Conference and speak to legislators about current issues. A few PL 3 residents had a chance to take advantage of the Home Health Care Forums. Home Health Care has been a political issue in this state and these forums were an attempt to gather information with which to address the legislators. Many residents posed interest in witnessing some of the possible proceedings on this issue. Also, the residents were all invited to attend the "Children With Special Needs and The Physician" conference. Only one resident was able to attend due to scheduling. Three residents attended a conference given by the Connecticut Chapter of the Academy of Pediatrics. Please see Appendix O for the pamphlet on this conference and examples of other opportunities given to residents. All of the conferences that the residents attended were met with positive overall satisfaction with the exception of one. Each resident that attended a function that did not fit into the curriculum evaluation forms, such as conferences, completed a one-page feedback form. Please see Appendix O for a copy of the one page feedback form and the data from the conferences attended.

The book Managed Care and Children With Special Health Care Needs, produced by the American Academy of Pediatrics, was ordered and distributed to the residents at the evening seminar on "Hospice and the Dying Child." Additional materials were also been made available for residents in the Primary Care Clinics, in order to facilitate their support of families. For example, brochures on Birth to Three, in both Spanish and English, were placed in the PCC at Connecticut Children's Medical Center, Saint Francis Hospital, and Burgdorf Health Center, to assist the residents in supporting families. The Project Coordinator also intermittently distributed packets of resource information. Please see Appendix O for a sample packet.

Activity 1.9 Recruit and admit students.

Recruitment was not necessary, as this rotation was part of the residency Program. The Children With Disabilities Rotation was represented at the Residency Program Fair on October 22, 1997, to provide additional information only. Medical students are admitted into the University of Connecticut Residency Program based on the Health Center's Admitting Committee's requirements. The Children With Disabilities Rotation was a requirement of all UCONN pediatric residents. Each June, a new class of residents entered the program and the PL 3's graduated. Each year there are generally 15 residents in Physician's Level 1 (PL 1); 15 residents in Physician's Level 2 (PL 2); and 15 residents in Physician's Level 3 (PL 3). These numbers include 2 Internal Medicine/Pediatrics residents in each year of the program. Occasionally, a resident leaves the residency program in the middle of the curriculum, and another resident is recruited to take their place. The residents who entered the rotation at an advance position were scheduled to receive orientation, and then he/she was placed into the module that best suited his/her background and need.

A total of 92 residents participated in this rotation. At the close of the project 48 residents were progressing through the program, 39 had graduated, and five had exited the program before graduation. The demographic information for the residents can be found on Table 2.

Activity 1.10 Schedule modules, seminars, and meetings.

All residents completed the competencies individually and according to each individual schedule. Orientation to the curriculum, for new residents, was initially given by the Project Coordinator immediately prior to the Family Centered Care Didactic. In year 3, orientation was given jointly by the Project Coordinator and the Medical Consultant as a separate, short, didactic conducted at one of the resident's regularly scheduled morning seminars. The didactic sessions were typically conducted at The University of Connecticut Health Center, Division of Child and Family Studies, with the exception of the Family Centered Care didactic. This session was held at the Family Center, at Connecticut Children's Medical Center. Due to the constraints of the resident's schedules on certain days of the week, some didactic sessions, in addition to Family Centered Care, were conducted at the Family Center.

Evening seminar topics were initially discussed at the first Advisory Board meeting. After discussion, the residents on this board brought the topics to the resident's business meeting and made decisions on what was of interest to the majority. Subsequently, the information from the consumer satisfaction form (discussed in Activity 2.4 of this report) gathered at the end of each evening seminar, was utilized to advise the Project Coordinator on other topics of interest. In addition, at the fourth seminar, a separate form asking specifically for topics of interest was handed out. Topics were then chosen from the list generated by this form.

Arrangements for the seminars, including speakers, time, place, etc., were made by the Project Coordinator. The seminars were opened to all attending physicians via e-mail invitations. The residents, all of the Birth to Three providers in Connecticut, and all of the students in the Early Intervention Specialist class (component 3 of this grant) were sent flyers inviting them to the seminar. Based on resident schedules and motivation, six evening seminars where scheduled to occur per year (instead of the initial 12). The list of seminars follows: "How to Give Bad News" on November 13, 1997; "Ethical Aspects of Medical Decision-Making" on January 29; 1998, "Using the Legislative Process" on March 19, 1998; "Hospice and the Dying Child" on May 21, 1998; "The Impact of Domestic Violence on Children" on September 24, 1998; "The Importance of Hope In The Lives of Children With Special Needs" on November 2; 1998; and "Learning and Using the Legislative Process" on February 4, 1999; "Coordinating Resources in Our Community" on April 15, 1999; "Real Pediatricians Provide a Primary Care/Medical Home for Children with Chronic Conditions" on September 2, 1999; "How to Give Bad News, 2" on December 7, 1999; "Pediatric Mental Illness" on March 8, 2000; and, "The Millionaire's Jeopardy Game: The Final Answer to the Question: What *is* the Disabilities Rotation?" on May 25, 2000. Two different flyers were developed for each seminar, one specifically for the residents (stating their stipend), and the other for all other possible participants.

The debriefing sessions occurred biannually for the first 2 years of the project. At least six of them occurred each block. They were scheduled during a time and at a place that was convenient for both parties involved. The debriefing sessions were audio taped. After the debriefings were completed, the audio tapes were transcribed and coded. This data was used to create a summary of the debriefing sessions, "An Exploration of Attitudes, Experiences, and Feedback." Please see Appendix I for this report. The evaluations of the residents, reviewed at the debriefing session, was filed in the resident's progress file at the Division of Child and Family Studies and a copy was placed in his or her file at the Connecticut Children's Medical Center. All of the debriefing dates were kept track of on a chart kept and maintained by the Project Coordinator.

A business meeting was held with all of the residents, the Project Coordinator, the Medical Consultant, and the three Chief Residents. This meeting was one hour long. The Project Coordinator facilitated this meeting. First the residents completed the pre-survey of background information on their previous experience with disability. The residents then broke up into small groups (all physician levels were represented in each group) and developed two lists. The first list was positive feedback about this rotation. The second list was what they would like to see changed and how to change it. When they were done, each group shared what feedback they produced. This feedback was considered and used to improve the program. The Project Coordinator also spoke about the importance of the evaluation forms and asked for volunteers to sit on the Advisory Council. The Medical Consultant inquired which residents still did not have a family from their continuity clinic to follow. She then made plans with those residents to help them find families who have a child with a disability.

During the third year, the new Medical Consultant, Dr. Eileen Fisk, met briefly with the residents at a regularly scheduled morning business meeting. She distributed 3X5 index cards to each resident and asked them to list 3 things they had learned so far in the rotation, and one thing they would change, if they could. From this information we determined the impact of the project on the then current residents and implemented changes to the curriculum to accommodate the most important criticisms. A memo was then sent to every resident listing the comments and noting how we had addressed each one. This gesture was received positively by the residents who subsequently said that they felt empowered to have brought about change in an important part of their curriculum. A copy of the comments and how each was addressed can be found in appendix P. Reviewing the resident's answers to the question "what have you learned so far?" is gratifying. The comments overall show that the residents were extracting and digesting the right lessons from the curriculum, in-spite of their sometime protests about the process.

To get feedback on how past residents are using information from this curriculum in their current practice a Post Residency Survey was developed. Graduates from 1998 and 1999 were questioned on their use of the knowledge gained from the curriculum. Twelve of the 26 graduates agreed to a telephone interview, and the results of the questionnaire will be further discussed in the "Impact" section of this report.

Objective 2.0 Implement a preservice personnel preparation program

Activity 2.1 Implement modules.

Please see Activity 1.5 of this report for refinement in the methodology and changes in the implementation of the material.

Residents have entered this program at different points in their residency (Physician Level 1, 2, or 3), and some senior residents who began this program at the inception of the grant did not complete all of the competencies. These residents were given choices as to what competencies they wanted to participate in to accommodate their individual needs and preferences.

Orientation to the rotation occurred before the first module of the curriculum. The Coordinator briefed the residents on the goals, objectives, curriculum, competencies, and resident and Coordinator responsibilities. Please refer to Appendix G for the Orientation Manual. This was a time for the resident to ask questions about the rotation itself, complete a "Resident Information" form (demographic data), and choose what specialty clinics they wanted to attend. The implementation of each module began with scheduling the resident for the didactic session. The resident received the schedule and an information sheet in their mailbox at Connecticut Children's Medical Center (see Appendix Q). In the didactic session, past competencies were reflected on, a pre-test was given, and upcoming components of the module were reviewed (including the scheduling of these components). After the didactic session, each component of the module was completed by the resident on the scheduled day. The resident then met with the Project Coordinator again, completed the post-test and module satisfaction and moved on to the next module. If there were scheduling difficulties, sometimes the resident would move on to the next module before completing the previous module. The time with the resident was limited and it was felt that it was better to progress to the next module, rather that miss an opportunity to interact with the resident.

To assist in the understanding of the information, often times the Project Coordinator would expand on the information presented in didactic sessions even further. For example, a case regarding medical services that had been recently heard in the US Supreme Court was presented and discussed (please see Appendix R for information on this case). In addition, there was a place on each self-evaluation form for the resident to write down any questions that they may still have had. These questions were often prompted while reflecting back on the visit. The Project Coordinator reviewed all of the self-evaluations that were turned in. If any of these questions existed, the Coordinator wrote the resident an explanation and often times included additional reading materials for further explanation or clarification. Some examples of the topics inquired about were: clarification on inclusion; Social Security benefits for long term, hospitalized, patients; Infoline's working hours; how Infoline monitors children that are not eligible for Birth to Three over time; Birth to Three provider's educational background; general information about the HUSKY Plan and the responsibilities of private preschools under IDEA.

In addition, as third year residents got closer to graduation and decided in what state they would reside, they often began to ask questions about the policies in other states. Two residents moved to Massachusetts. They were given numerous contact names, phone numbers and addresses of key players in different important agencies that work with children with special needs. One of these residents interviewed the director of Early Intervention in MA for the "Interview an Agency Administrator" component under the Interagency Collaboration, Service Integration, and Resource Allocation Module. He inquired about, for example, the referral process, eligibility requirements, and funding sources in MA that may differ from Connecticut's process. Another PL 3 resident planned to move to California and collected information about that state's system. Another resident who already knows he will be staying in CT and in the community where he lives currently. The Project Coordinator arranged for his early intervention and school visits to be in his own community. He felt it was a great benefit to learn the key players in his community and began to develop a collaborative relationship with them. Both systems readily accepted and were more than willing to host the resident.

The Project Coordinator attended different informational meetings to increase her own understanding of the systems, thus increasing her effectiveness in training and supervision. For example, the Project Coordinator attended a meeting at Connecticut Children's Medical Center, on The Birth To Three System in CT. The meeting was sponsored by The Children's Health Care Network. Much of the information obtained at this session was distributed to the residents as additional information. She also attended the conference, " Children With Special Health Care Needs and the Physician" and "Natural Environments Part 2; Implementation in the Community" teleconference.

Activity 2.2 Utilize home and school visits.

Home and school visits were utilized by each resident as s/he came upon that particular competency. The program sites that were used are listed in Activity 1.7 of this report. As reorganization occurred in the hospital, the specialty clinics varied to some degree. Outreach was ongoing for sites to visit. The Project Coordinator focused much of her efforts on bringing more families, natural environment sites, school sites, and specialty clinics onto the project. Please refer to Table 1 on outreach.

Residents utilized these home and school visits not only to improve their skills and knowledge as a pediatrician, but to also support their families more. Residents applied the knowledge they learned on collaboration to interact with both the Birth to Three programs and the school programs of their patients. For example, one resident used her knowledge of the special education and the law to advocate successfully for her patient so he would not lose services. Another resident collaborated successfully with her patient's Birth to Three program to advocate for the child's placement in the school system (the child was transitioning). Please see Appendix I for more examples.

All of the community programs and the families received stipends for participating. Stipends were distributed in December 1998. In year 3 of the grant, stipends were paid in May 1999 and December 1999. Stipends were further distributed in February 2000, and the final payments will be distributed during September 2000. The programs in Connecticut Children's Medical Center did not receive stipends. State run programs (Early Intervention programs and daycare programs) were given a textbook of their choice in lieu of a stipend.

Activity 2.3 Utilize instructional technology.

Communication between The Division of Child and Family Studies, the resident, and different sites was ongoing and utilized many different methods, including: letters, beepers, telephone, fax, and e-mail.

VCR tapes were utilized to add a different dimension and exemplify the concepts in the didactic material. For example, The Principles of Family Centered Care video was used during the Family Centered Care didactic to demonstrate the nine principles in action. Not all of the residents enjoyed and learned from the videos, so they were utilized accordingly. All of the videos were reviewed again before the final printing of the curriculum.

Activity 2.4 <u>Implement seminars</u>.

The residents, the Birth to Three providers in Connecticut, and the students in The Early Intervention Specialist Program (Component 3 of this grant) were sent flyers inviting them to the evening seminars. The seminars were opened to the hospital faculty via e-mail. Only the residents received a $50.00 stipend for attending and all participants received dinner. The speakers present at these seminars came on a volunteer basis. A resident was included on every panel of speakers to present a case study exemplifying the topic area. These case studies were true cases that involved that particular resident and often times, other residents in the audience.

Due to resident schedules and motivation, the number of seminars was reduced from twelve per year to six per year. However, even this reduced number was difficult to schedule, and the total number of seminars for the 3 years of the project was twelve. Following is a list of all the seminars:

1. "How to Give Bad News" on November 13, 1997
2. "Ethical Aspects of Medical Decision-Making" on January 29, 1998
3. "The Legislative Process" on March 19, 1998
4. "Hospice and the Dying Child" on May 26, 1998
5. "The Impact of Domestic Violence on Children" on September 24, 1998

6. "The Importance of Hope in the Lives of Children with Special Health Care Needs" on November 2, 1998
7. "Learning and Using the Legislative Process" on February 4, 1999
8. "Coordinating Resources in our Communities" April 15, 1999
9. "Real Pediatricians Provide a Primary Care/Medical Home for Children with Chronic Conditions" September 2, 1999
10. "How to Give Bad News, 2" December 7, 1999
11. "Pediatric Mental Health: Where are We? Where are We Going? March 9, 2000
12. "A Millionaire's Jeopardy Game, the Final Answer to the Question: What *is* the Disabilities Rotation?" May 25, 2000

The panel of speakers at the first seminar included two key note speakers, Bob Greenstein, MD, and Tim Kelly, MD, and Ms. Molly Cole (a parent), Dr. Michael Guerrera (a pediatric resident studying Oncology), and Mary Anne Meade (the Network Coordinator of Parent to Parent). There were a total of twenty-six consumer satisfaction forms completed. This total includes all participants, not only residents, and the outcomes were all positive.

The second seminar's panel of speakers included, Marilyn Sanders, MD, Carol Leicher, MD, and Nancy Williams, RN. JD. LL.M. There were a total of 16 consumer satisfaction forms completed. This total includes all participants, not only residents, and the outcomes were all positive.

The third seminar, on the legislative process, had speakers who included The Honorable William Aniskovich (Senator, 12th District), Ms. Judi Blei (Governmental

Relations, American Academy of Pediatrics), The Honorable William R. Dyson (State Representative, 94th District), The Honorable Mary Eberle (State Representative, 15th District), and Dr. Eileen Fisk (pediatric resident). There were a total of 16 consumer satisfaction forms completed. This total includes all participants, not only residents. The outcomes were for the most part positive, with some minor disagreement as to whether or not the objectives of the session were met.

The fourth seminar, on the Hospice experience, had speakers who included Stanley Aronson, MD, Carol Leicher, MD, Eileen Gillan, MD, and Andrew Capraro, MD (pediatric resident). There were a total of 29 consumer satisfaction forms completed. This total includes all participants, not only residents. The outcomes were for the most part positive. A few statements were rated less than neutral, but overall, the means were positive.

The fifth seminar, on child abuse, had speakers who included Skip Berrien, MD, Linda Harris, MSW, Garry Lapidus, PA-C, MPH, Brian Lamoueux, MD (pediatric resident), Jim Loomis, Ph.D., and Philip Scribano, MD. There were a total of 34 consumer satisfaction forms completed. This total includes all participants, not just residents. The outcomes were positive, with all of the means, but one, above 4.0 on a 5.0 Likard Scale. The one exception was 3.85, still in the positive realm.

The sixth seminar, on Hope, had speakers who included Alan Crocker, MD, Ms. Molly Cole and Jim O'Connor, MD (pediatric resident). There were a total of 22 consumer satisfaction forms completed. This total includes all participants, not just residents. The outcomes were positive, with all of the means, but one, above 4.0 on a 5.0 Likard Scale. Again, the one exception was 3.85, still in the positive realm.

The seventh seminar, on the legislative process, had speakers who included The Honorable William Aniskovich (Senator, 12th District), Ms. Judi Blei (Governmental Relations, American Academy of Pediatrics), The Honorable William R. Dyson (State Representative, 94th District), The Honorable Mary Eberlè (State Representative, 15th District), Teresa Olivera, MD (pediatric resident), and Robert Zavoksy, MD. There were a total of 23 consumer satisfactions completed (13 residents and 10 non-residents). The outcomes were positive, with all of the means above 3.5 on a Likard Scale.

The eighth seminar, on community resources, had a panel of speakers who included: Leo DiStefano, MD, a general pediatrician, Linda Goodman from the Department of Mental Retardation, Jan S. Gilbert from the Social Security Administration, Ann Hynes, M.Ed., from the Children's Health Project, Ann Gionet from the Department of Public Health, and Pat O'Connor, Ph.D. from the Rocky Hill Board of Education. The residents were represented by Jennifer Gannon, MD, and by Erik Cohen, MD. There were a total of 12 consumer satisfactions completed (11 residents, and 1 non-resident). The outcomes were positive, with all the means above 3.6 on a 1-5 Likart Scale. Only one mean was below 4.0.

The ninth seminar, on the Medical Home, had speakers who included W. Carl Cooley, MD, the Medical Director of Crotched Mountain Rehabilitation Center, and Jennifer Gannon, MD, a resident. There were a total of 22 consumer satisfactions completed (15 residents, and 7 non-residents). The outcomes were positive with all the means above 3.6 on a 1-5 Likart Scale.

The Tenth seminar, on "How to Give Bad News" was repeated from a previous presentation at the resident's request. The format, however, was quite different, yet it conveyed the same important message. The speakers included Bob Greenstein, MD, a geneticist, Steven Bergstrom, MD, an oncologist, Jim Loomis, PhD, a psychologist, and Ms. Molly Cole, activist and parent. The residents were represented by Darvey Koller, MD. There were a total of 31 consumer satisfactions completed (23 residents and 8 non-residents). The outcomes were positive, with all the means but one above 4.0 on a 1-5 Likart Scale.

The eleventh seminar was on pediatric mental health, a topic the resident's had been requesting for some time. The speakers included Karen Andersson, Ph.D., Director of Mental Health at Connecticut's Department of Children and Families. David Parella, Director of Medical Administration at Connecticut's Department of Social Services, and Dawn Henschel, Parent, and Director of Transitioning Youth Programs, Connecticut Department of Mental Health. A total of 19 consumer satisfactions were completed (15 residents and 4 non-residents). This was the least well received of the 12 seminars, in large part because it became a forum for political bickering between the various departments of the State of Connecticut. The audience reacted strongly to the speaker's political undertones, and the outcomes show only 2 above 4.0 on 1-5 Likart Scale. Nevertheless, most of the outcomes were above 3.0, still in the positive range.

The twelfth seminar was entirely different from any of the others, and was designed as a wrap-up and overview of the 3 year program. We devised a trivia game based very loosely on the television game shows of "Jeopardy" and "Who Wants to Be a Millionaire?" We developed 120 multiple choice questions that spanned the content of the entire 3 years of the curriculum. The true curriculum questions were interspersed with comic relief questions to lighten the evening and entertain the audience and the teams. Two teams of residents were organized to compete with each other. The "girls" team and the "boys" team. Teams were allowed to poll the audience once, call a friend once (ask someone in the audience, rather that telephone), and narrow the answers once to 50/50. Small gifts were distributed to all members of the teams, and $10 gift certificates were awarded to each member of the winning team (in addition to the usual stipend). It was an evening of fun as well as a learning opportunity for the residents. Since the content of the seminar was very specific to the resident's 3 year curriculum, and since we knew that this was to be the final seminar, we decided to restrict it resident participation only. Therefore, the number of participants is markedly lower that for any other seminar. There were a total of 10 consumer satisfaction forms completed, all of them from residents. The outcomes were positive with all the means above 4.0 except one. Overall, for the 12 seminars, consumer satisfactions were completed by 271 attendees, 183 from residents, and 88 from non-residents. For all attendees, the mean for each question was above 4.0, with the mean across all questions above 4.4. For resident attendees, the mean for each question was above 4.0 with one exception. The mean across all questions was also 4.4. Each seminar had standard questions and questions specific to the topic at hand. Comparisons of satisfaction with the standardized questions for each seminar can be found on Table 3. The 3 most popular seminars according to overall satisfaction was "How to Give Bad News 1," "The Ethical Aspects of Medical Decision Making," and "Using the Legislative Process." The least popular seminar was "Pediatric Mental Health."

Every seminar was video taped, so that those residents unable to attend could watch the video at their convenience.

Activity 2.5 Supervise clinical practica.

All visits were supervised. Who did the actual supervision was not on a set schedule. It fluctuated as to which residents attended visits with staff from the Division of Child and Family Studies and which residents were supervised by staff at the site. Randomly, the staff, including the Project Coordinator and the Medical Consultant accompanied the resident to the visit. In these cases, the experience was reflected upon directly after the visit. At different points of intense work, (for example during intense outreach, preparing for seminars or writing reports) the supervision by the Division staff in the field was less. If the preceptor was not a staff member from the Division, s/he could be one of many different people at the clinic/community visit. For example, it could have been the Project Coordinator, the Medical Consultant, the mother at the home visit, the nurse practitioner or physician at the specialty clinic, the teacher in the classroom, or the therapist at the early intervention home visit. The resident completed his/her own self-evaluation and the preceptor completed the preceptor form after the visit. Both the preceptor forms and the self-evaluations were placed in the resident's progress file at the Division of Child and Family Studies. A mailbox was set up for dropping off forms at Connecticut Children's Medical Center for the resident's convenience. The information from these forms was recorded into the data base as it was turned-in. Residents had access to their progress files at any time.

Activity 2.6 Implement State and Local Board Participation.

The schedule of the Interagency Coordinating Council (ICC) was obtained, And attempts were made to match resident schedules with those who had indicated a desire to observe these meetings. A total of 10 residents attended the ICC, and 2 residents attended the Local Interagency Coordinating Council (LICC) in Hartford. All residents were accompanied by the Project Coordinator. A brief session was held with the resident before the meeting to inform him or her of what had occurred at the previous meeting. A quick debriefing also occurred after the meeting to reflect on the issues that had been presented. The residents also spoke with the physician who sits on the ICC before the meeting began. He spoke about the council and his role on it as a physician and as an advocate for children. One resident attended an ICC meeting and heard what Connecticut was planning to do for Newborn Hearing Screening. She felt very strongly about who should be informed of the results of these screenings and planned on writing letters to the appropriate officials to advocate for families receiving this information, in addition to the primary care provider.

Activity 2.7 Convene Higher Education Council.

Please see component 3 of this grant.

Activity 2.8 Facilitate competencies.

As adult learning dictates, the curriculum was written to allow for individual interests and preferences to surface. The competencies were facilitated based upon the individual resident's style of learning and need/interest for information. For example, some residents preferred to learn the information in didactic sessions through dialogue with parents and professionals. Others preferred to listen and just ask questions when they were confused. These different styles of learning were taken into account when planning and conducting sessions. The year of residency, the schedule, and the completion of past material were all taken into account when facilitating competencies. Since residents entered this program at different points in their residency (Physician Level 1, 2, or 3), some senior residents were unable to complete the full schedule of competencies. These residents were given choices as to what competencies they wanted to participate in to accommodate their individual needs and preferences. Other residents proceeded through the modules in their sequential order. All of the competencies for each module were reviewed with the resident during the didactic session for that module. The Project Coordinator prepared the resident at this time for his or her upcoming visits. This time was also to get questions answered. In addition, each of the competencies from the previous module were reviewed during the didactic session in order to answer questions, get and give feedback, and review how the material was implemented in practice.

The project encountered a few problems implementing the competencies, but these were generally resolved without difficulty. For example, one solution was to give The Primary Care Center attending physician a copy of the schedule for the rotation, so that the staff would know what residents needed to leave the clinic on time. Prior to this the residents had been retained in the Primary Care Clinic or PCC for further work and thus, arrived late to their visits. In addition to giving the attending physician the schedule, the sites were given the resident's beeper numbers.. This eliminated unnecessary driving when a visit was canceled or postponed. The residents were also given the site's number, thus, they could call the site directly if they had to cancel at the last minute due to illness, car troubles, etc. Lastly, the Primary Care Center attending physician and the Chief Residents assisted the Project Coordinator to change the schedule when certain visits were needed on certain days, for example, NICU Follow-Up Specialty Clinic only occurred on Tuesdays. Since most residents were not scheduled on Tuesdays, it was resolved that certain residents could rotate through this curriculum on Tuesday when necessary. Finally, there was a change in the flexibility of the schedule. The Chief Residents attempted to get the block schedule completed earlier. This allowed the Project Coordinator time to schedule the residents and put in special requests for certain days before the schedule was distributed to the staff. The flexibility in the schedule allowed residents to have more choices in where their visits took place. For example, if a resident wanted to attend a certain specialty clinic that only took place on a certain day, the Project Coordinator was able to request the resident's participation on that particular day.

Objective 3.0 Evaluate a preservice personnel preparation program

Description of Project Evaluation Data System

The Physicians Training Project had a multiple component data system for evaluation. Evaluative data was collected from the beginning of the project. The data were incorporated into a comprehensive system beginning in October 1997, and the system was refined over the course of the project as necessary. During the second half of 1999, a major revision was made to the data system reflecting the changes in the curriculum structure and requirements.

The data system has been used both formatively, to better manage and coordinate the residents' ongoing participation in the curriculum, and summatively, as an evaluative tool for the training. It has served as a:

> vehicle for monitoring the progress of the residents through the curriculum,
>
> tickler system for improving completion of paperwork,
>
> evaluation of resident satisfaction with the curriculum,
>
> evaluation of amount learned through the comparison of pre and post-tests,
>
> evaluation of self and preceptor ratings of the learning activity visits,
>
> summary of role of other participants,
>
> bookkeeping system for payment of other participants.

All quantitative data were entered, maintained, and analyzed using SPSS Data Entry and SPSS for Windows data system. A simple system using the Table function in Word was used to record, organize and explore qualitative data.

Activity 3.1 Evaluate student status.

Data System:

Resident Background and PL Information. Two simple files contained basic information about the residents participating in the program. The first, a resident information file, included demographics (Table 2), work location, and status (active, graduated or exited) information. This file also identified the few participating residents who followed a more abbreviated curriculum for the medicine/pediatric program. The other file included the beginning and ending dates for each PL year for each resident. (Most residents followed the hospital's July to June academic year but a few were on unique time lines). The PL file was used as a reference file (Table file in SPSS) and matched to the status and all resulting analytic files so that the PL can be defined for each resident at the time he or she completed each learning activity in the curriculum.

Status File and Reports. A status file was maintained to track all learning activities undertaken by the residents including didactic sessions and required module visits. Information included dates, locations, and any participant pay information. Completion indicators and dates for all pre and post-tests, didactic session and module satisfaction surveys, and self and preceptor evaluations of visits were noted. Two periodic reports were prepared. A module and visit report listed all components (didactic sessions and visits) for each resident and the module paperwork. It was used by the Project Coordinator to aid in scheduling and in monitoring paperwork compliance. It served as a tickler file for the coordinator to know when module completion paperwork could be distributed. A report update was run at the beginning of each block (monthly), and whenever the volume of activity warranted. A paper work report focused on the self and preceptor evaluations and was used to monitor their completion. It was run every two weeks.

Analysis of the status information was made using three units of analysis. First, resident progress (what and how much is completed, in progress, etc.) was explored with an aggregated resident file; module information (e.g., how many total didactic sessions presented) was analyzed for each module; and finally, individual component (visit) information was analyzed through a component's file. The data were initially entered at the module level and aggregated and dis-aggregated to the resident and component files, respectively. All data in the system were converted to match the final module and component curriculum (defined in year 3 of the project), as if all were completed under the final system. Module completion and resident progress were evaluated using the new curriculum. Internal Medicine/Pediatrics residents were measured against their own curriculum schedule.

Over the course of the 3 years, a total of 92 residents spent some amount of time progressing through the curriculum. This ranged from as little as six months, for those who graduated the year the project began, to as long as the full 3 years, for those who started residency the year the project began. Because we continued with the curriculum for an unfunded six-month extension, in the final year there were PL-1 residents who benefited from the project for a full year, who would otherwise have received only six months of the curriculum.

Pl-1 and PL-2 residents followed the curriculum in ordered sequence. As each PL-3 resident began the first ambulatory block of the third year, s/he met with the project coordinator to discuss the upcoming year. Competencies not yet completed were reviewed and the year's schedule tailored to meet the resident's needs and interests as much as possible. Please see tables 4 and 5 to view the resident's progress in the curriculum divided by time period.

Activity 3.2 Evaluate program status.

Evaluations of the didactic sessions and modules were completed by the residents after each didactic session or at the completion of a module.

Data System:

Progress in each module. Progress was evaluated by the data system. As can be expected, because more residents entered the first year than entered any other year, the most progress was made in the first third of the curriculum. All 92 (100%) residents completed some components of Family Centered Care, and 55 (60%) completed all components of the module. Ninety-one (99%) residents completed some components of Early Intervention, and 58 of these (64%) completed all components of the module. Eighty-nine (97%) residents completed some components of Special Education, and 30 of these (34%) completed all components of the module. Eighty-three (90%) residents completed some components of Roles of Other Professionals, and 33 of these (40%) completed all components of the module. Sixty-four (70%) residents completed some components of Communication Skills and Team Participation, and 2 (3%) completed all components of the module. Forty-two (46%) residents completed some components of Interagency Collaboration, Service Integration and Resource Allocation, and 9 of these (21%) completed all components of the module. Forty-seven (51%) residents completed some components of Advocacy and Responsibility and the Legislative Process, and 3 of these (6%) completed all components of the module. Please see table 6 for a summary of resident progress by module and class year, across all 3 years of the project.

A shell was created to keep track of what visits were missed by each resident and why. This aided in the completion of the evaluation forms (reviewed later in this report). Initially, no accommodation had been built into the schedule to allow for snow days at community schools, or for sick days for the residents, or for any other reason that might be a legitimate cause of a missed visit. This has contributed greatly to the number of incomplete modules for each resident. Therefore, during the restructuring of the curriculum in 1999, extra slots of time were built into the schedule so that missed visits could be made-up.

Session, Module and Seminar Satisfaction. The session satisfaction questionnaire originally consisted of 20 questions. During the 1999 restructuring of the curriculum, this was pared down to 11 items: 7 questions concerning the role of the facilitators (e.g., preparation, organization, knowledge, enthusiasm, etc.), 3 questions on the content of the session (e.g., objectives, materials, usefulness, etc.), an overall rating of the session, and 1 open ended question (what could be added or omitted). The module satisfaction questionnaire originally consisted of 14 items. Again, during the restructuring of the curriculum, this was pared down to 9 questions. Six focusing on the presentation and home, clinic, and community experiences, an overall evaluation of the module, and 2 open ended questions: what were the benefits of the module to the pediatrician? and, did the resident have suggestions for improving the module? All items, except the open ended questions, were rated on a five point Likert scale from strongly disagree to strongly agree with the statement "I was satisfied with". The data system consisted of two files, one for session satisfaction and one for module satisfaction. Each resident contributed a record in each of the files for every didactic and module rated. This system allowed for the evaluation of satisfaction with didactic session and entire module curricula both overall and by module.

The module satisfaction form was originally presented only at the completion of the module. To conduct a timely formative evaluation of the modules, some residents were asked to complete the module satisfaction form before their final completion of the module. (All residents had completed the didactic and some of the visits.) The data showed that all of the didactic sessions had scores well above 4.0 on a 1-5 Likart scale, indicating high satisfaction with the didactic sessions. Module satisfaction data are a little different. Data from "Module Satisfaction by Specific Question, across all Modules" showed that most of the questions scored above 4 on a 1-5 Likart scale. Three items scoring less than 4 were "quality of the readings," "methods and techniques," and "audio visuals." These concerns were addressed during the ongoing refinement of the curriculum, and greater satisfaction was noted after the change. Proof of this can be found in the graduating resident's comments during their closure session with the Medical Consultant and Project Coordinator (appendix T), which is further discussed in the Impact section of the report. Overall module satisfaction for each module showed scores above 4.0 for all 7 modules. Special Education, Interagency Collaboration, and Advocacy & Responsibility were the most satisfying modules, according to these scores.

In addition to the modules, residents attended one or more seminars presented or coordinated by the division. Satisfaction with these presentations was monitored with a questionnaire similar to the session satisfaction questionnaire. A separate file was maintained for overall and item analysis, and the results are discussed in activity 2.4.

Pre and Post-tests. Each pre and post-test was scored manually. The tests for each of the 7 modules varied in length and have been revised as changes have been made in the curriculum organization and content. An important change was made in these tests in the final year of the program, when the curriculum underwent restructuring. At that time, the pre and post tests were reformulated to reflect the resident's comfort level with each of the concepts introduced in the modules. Prior to this, the pre and posts tests had been knowledge based, and required a great deal of time to complete. This consumed a large part of the time devoted to the didactic session, as well as generally being unpopular with the residents; therefore, the decision was made to convert from a knowledge based test, to a comfort level test. Because these two types of tests may be thought to measure different abilities, we have analyzed them separately and will discuss them separately. All scores were converted to percent correct for comparison across test versions and modules. For data entry and analysis, a simple test score file was created consisting of one record for each resident for each module that included his or her scores on the pre-test and post-test for that module. There were a total of 277 pre-tests taken and a total of 179 post-tests taken. Data in this report consist of the paired t test scores on the pre-tests and post-tests for each module taken (table 7), as well as the individual percentage scores for all the pre and post tests. Please see table 8 for this information broken down by type of resident (pediatrics and medicine/pediatrics). Not all the numbers for the pre and post tests match, as some residents took a pre test for a given module, but not a post test. Also, a few residents completed a post test in some modules without having done a pre test in that module. Paired comparisons of scores are also included using those residents who have completed both a pre and post-test for the module to evaluate the effectiveness of the training (table 7).

From the pairs of pre and post-tests we can gather information about growth, learning and the effectiveness of the training. The following is a module by module descriptive breakdown of paired t test results.

Module 1, Family Centered Care:

Knowledge based pre test mean score: 57.48, SD 12.37

Knowledge based post test mean score: 69.55, SD 12.48

Paired differences mean: 12.07, SD 13.44, t value 4.84, df 28, 2-tail significance 0.000

Comfort level pre test mean score: 13.2, SD 4.83

Comfort level post test mean score: 73.33, SD 11.98

Paired difference mean: 56.67, SD 11.18, t value 18.49, df 11, 2-tail significance 0.000

Across the board for this module the difference was significant. It can be especially appreciated in the comfort level testing, where a clear change can be seen.

Module 2, Early Intervention:

Knowledge based mean pre test score: 61.09, SD 9.92

Knowledge based mean post test score: 79.1, SD 8.95

Paired difference mean: 17.19, SD 10.73, t value 8.32, df 26, 2-tail significance 0.000

Comfort level mean pre test score: 19.47, SD 7.62

Comfort level mean post test score: 81.67, SD 13.98

Paired difference mean: 61.67, SD 12.83, t value 11.77, df 5, 2-tail significance 0.000

Again, we can see a clear and significant difference in the pre and post tests with both formats, indicating a certain increase in knowledge and comfort with the material.

Module 3, Special Education:

Knowledge based mean pre test score: 65.90, SD 12.94

Knowledge based mean post test score: 74.60, SD 9.14

Paired difference mean: 5.86, SD 10.93, t value 2.84, df 27, 2-tail significance 0.009

Comfort level mean pre test score: 28.00, SD 12.43

Comfort level mean post test score: 76.00, SD 16.71

Paired difference mean: 56.17, SD 20.19, t value 6.81, df 5, 2-tail significance 0.001

This module, like the 2 before it, shows growth in the resident's grasp of the material.

Module 4, the Role of Other Professionals:

Knowledge based mean pre test score: 54.88, SD 17.32

Knowledge based mean post test score: 79.83, SD 13.10

Paired difference mean: 22.23, SD 14.55, t value 7.16, df 21, 2-tail significance 0.000

Comfort level mean pre test score: 28.00, SD 12.43

Comfort level mean post test score: 100.00 (only one post test completed under these circumstance)

Although we cannot perform a paired t test for this analysis, the knowledge based test indicates a significant difference for the pre and posts test results.

Module 5, Communication Skills and team participation:

Knowledge based mean pre test score: 66.37, SD 16.17

Knowledge based mean post test score: 80.23, SD 13.87

Paired difference mean: 11.00, SD 13.76, t value 2.88, df 12, 2-tail significance 0.014

Comfort level mean pre test score: 31.29, SD 14.23

Comfort level mean post score: none completed

Paired difference: unable to calculate

As in module 4, we could not calculate a paired t test for comfort level scores; however, also as in module 4, the knowledge based test results show growth in the resident's grasp of the material.

Module 6, Interagency Collaboration, Service Integration, and Resource Allocation:

Knowledge based mean pre test score: 67.21, SD 16.17

Knowledge based mean post test score: 85.73, SD 11.65

Paired difference mean: 18.36, SD 17.52, t value 3.48, df 10, 2-tail significance 0.006

Comfort level mean pre test score: 28.30, SD 9.80

Comfort level mean post test score: 83.00 (only one post test completed under these circumstances)

Module 7, Advocacy and Responsibility and Legislative Process:

Knowledge based mean pre test score: 55.10, SD 19.21

Knowledge based mean post test score: 80.00, SD 12.85

Paired difference mean: 17.00, SD 21.44, t value 1.77, df 4, 2-tail significance 0.151

Comfort level mean pre test score: 39.00, SD 12.05

Comfort level mean post test score: 71.00, SD 17.47

Paired difference mean: 28.80, SD 29.55, t value 2.18, df 4, 2-tail significance 0.095

This one module failed to show a significant change in pre and post test scores. The likely explanation is the low n, referring to the low number of residents who completed both pre and post tests for this final module of the project.

All modules together:

Knowledge based mean pre test score: 62.82, SD 12.81

Knowledge based mean post test score: 76.87, SD 12.09

Paired difference mean: 14.05, SD 14.20, t value 11.5, df 134, 2-tail significance 0.000

Comfort level mean pre test score: 13.67, SD 5.25

Comfort level mean post test score: 73.3, SD 11.98

Paired difference mean: 59.67, SD 11.18, t value 18.49, df 11, 2-tail significance 0.000

What does all this data tell us? Well, for one thing, the residents *did* learn about children with disabilities and their families as they progressed through the 3 years of residency, and through the 3 years of this curriculum. We can tell from the knowledge based tests that their knowledge increased a significant amount between the beginning and the end of each module, except for the last. We can tell from the comfort level tests that the residents felt infinitely more comfortable with the material at the end of each module, than they did at the beginning of each module. Unfortunately, we can't be 100% sure that the resident's increase in comfort is due solely to this curriculum. However, since very little of this material is covered in other rotations of the residency program, it seems relatively safe to say that the increase in comfort level is due, in large part, to what was learned through the children, the families, the community visits, and the written material of this curriculum. Further proof of this can be found in the impact section of the report, where we discuss a post-residency telephone survey of physicians in practice. Pediatricians who graduated from this program are interacting with early interventionists and school systems on a regular basis. As one of those physicians stated: "I know so much more than my colleague who graduated from another program at the same time as me."

Self and Preceptor Evaluations. The research assistant produced reminder sheets each block for residents, listing what forms they had due. This helped to increase the return of self-evaluations. Each learning activity (visit) had unique aspects to its contribution to the curriculum. The forms for the resident's self evaluations and the preceptor's evaluations of the residents reflect this complexity. Each form was specific to the nature of the visit and contained different questions. Adding to this complexity, the self and preceptor forms were modified several times as the curriculum was revised. Several themes, central to the purpose of the curriculum, run through all of the forms. It is these overall themes that comprise the data selected for entry and analysis.

For the resident self-evaluations the themes are:

1. whether the resident had the opportunity to observe what was learned in the didactic
2. whether the visit increased the resident's knowledge as a physician
3. resident's overall satisfaction with the visit

All the questions on each self-evaluation that pertained to these themes were identified by the Project Coordinator. Project staff then hand scored each evaluation (through its changing versions) to indicate affirmative and negative responses on all questions pertaining to the three themes for each resident's completed form. The percent of questions answered affirmatively comprise the residents' score on that concept.[1]

In addition to the above themes, two key questions identified:

1. Overall, how satisfied were you with the visit?
2. Did you benefit from this visit as a physician?

The first question was redundant with one of the concepts. The analysis of each completed resident self-evaluation thus included percent scores on the three concepts and their responses to the second yes/no question. Please see table 9 for the data from the self-evaluation forms broken down by module and physician level, and table 10 for this data by all residents combined. Please see the next section of this report, Evaluation, for analysis of these tables.

As with the self-evaluations, initially, the process was the same for the preceptor forms. The three concepts were:

1. was the information obtained in the didactic used?
2. what was the general performance of the resident?
3. did the preceptor see benefits of the visit for him or her self?

During the restructuring of the curriculum it was realized that, even though many of the community preceptors were answering the first question in the affirmative, few of them had actually participated in a didactic session. Consequently, they were not in a position to judge if the actual didactic material had been used by the resident, although they could certainly judge if the resident had acted appropriately. Therefore, this

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[1] There were some unanswered questions; if more than three quarters of the questions comprising a concept were left unanswered, the concept was considered missing.

question was dropped from the preceptor's evaluation form in the final year of the project.

Two specific questions were:

1. Did the physician demonstrate professionally appropriate behavior?
2. Overall what was the quality of the resident on the visit?

Both files were matched against the component activity file for information about the visit including its time of occurrence, location, resident's PL, etc. Analyses for this report include average concept scores and percents of residents or preceptors responding yes to the two specific questions. The overall preceptor scores are presented for each module over the 3 year span. We have further broken out preceptor data in 2 sub-categories: family preceptor and educator preceptor. Please see tables 11 & 12 for the analysis of the data of the preceptor forms. Please see table 13 for the qualitative data chart produced from the small number of Form B's that were returned. The overall comments have all been positive. As with the resident self-evaluation data, the preceptor data will be more closely discussed in the evaluation section of the report.

A new preceptor form created in year 2 of the project for the didactic sessions. This form helped to keep track of things such as participation by the resident, how many participants were in the session, etc. This information was utilized primarily to assist in the completion of the evaluation of the resident (which is described below). Please see Appendix F for an example of this form.

Resident Biannual Debriefings and Evaluation. As described above in the section on revisions to the curriculum content, the evaluation of the residents was on-going, and a number of formats were used over the course of the project. Residents were rated on a biannual basis by the Project Coordinator and/or research assistant and then participated in biannual debriefing sessions with the project's Medical Consultant.

The project staff rated the residents' professional attitudes and behaviors, commitment to scholarship, humanistic qualities, and moral and ethical behavior. The ratings were based on their own experiences with the resident in didactic sessions, the preceptor ratings, the residents' record of attendance and his or her completion and timeliness of curriculum paperwork. Residents were rated on approximately 18 quality measures on a scale from inadequate (6) to outstanding (1.) This evaluation form is used as a tool in every rotation of the residency program to ensure that each resident is performing adequately throughout the program. It proved useful for our purposes, and was used by the Medical Consultant to aid in the overall evaluation of each resident. Since the information on the form does not impact this project in any way, and since the residents were evaluated for this report using other methods, the data from the residency program evaluations have not been tabulated. However, suffice it to say that every resident was given a passing grade, and some received outstanding notations, while others were acknowledged to have performed adequately. Please refer to appendix H for a copy of the evaluation form.

For the first 2 years of the project, the debriefing sessions with the Medical Consultant were audio taped and transcribed. Transcripts were carefully reviewed using a qualitative methodology for emerging key concepts. The concepts were recorded and compiled using a simple word table in the word processing software. A narrative description of the concepts is included in the analysis. Please see Appendix I.

Activity 3.3 <u>Evaluate community status</u>.

As listed in Activity 1.7, outreach to new programs continued throughout the project. Please refer to Table 1 for a breakdown of the outreach efforts. Outreach to update programs already in the project also occurred. The Project Coordinator spent time visiting programs in the system to give an overview of the project and to show how their program visit fits into the curriculum as a whole. New evaluation forms were shared with the programs and questions were answered. Each preceptor at each program was asked to fill out the preceptor form. This gave him/her a chance to comment on not only the performance of the resident, but also on the program and how it was running.

All of the community programs involved in this project received stipends or in the case of state run programs, books, for participating. The stipend informational form filled out by each program was kept on file at the Division.

Data System:

Bookkeeping. Many of the locations used for residents' observations and visits were compensated for their time and effort with a participation stipend. Several files were created to keep track of the "pay events" (those involving a family, school, or other entity that was entitled to a stipend), the recipients of the stipends, and the payments as received. The pay event file was created from the status file without duplicated data entry. A complementary payee file contains one record for each payee that included the payees' name and address, social security number or federal tax identification number, and any other information necessary to make the requisite payment. Because there were several different payment models (some cannot accept cash and were given books or learning materials as honoraria) and thresholds (number of visits needed for payment), this information was included in the payee file. The payee information was matched to the pay event file to determine what stipends needed to be paid. A third payment file kept track of the stipends already paid to avoid duplication.

While not part of the data analysis, incorporating this information into the data system reduced the amount of separate entries thereby reducing time needed and potential errors.

Evaluation

Resident progress data has been tracked from the initial pilot period of 7/1/96-12/31/96 (time block 1), but this report includes the full resident progress data from the grant years of 1/1/97-12/31/99 (time blocks 2-7), plus a six month unfunded extension from 1/1/2000-6/24/2000 (time block 8). The remainder of the data is from the period 1/1/97-6/24/2000, which includes the six months unfunded extension. Much of the data are presented both overall and by resident year. The majority of the residents were in the program for three years (PL 1, PL 2, and PL 3), although a few transferred in and out and spent as little as a year in this residency program. Residents enrolled in dual residency, Internal Medicine and Pediatrics, were in the program for four years.

Demographics. The vast majority of residents were between the ages of 25 and 34 at Orientation. Ethnicity included Asian, Caucasian, Haitian, Indian, Latino, and others. Most were of American origin, but many countries were represented. Table 2 contains these and additional data on demographics.

Progress through curriculum. Tables 4 and 5 contain a listing of all residents by time block, I.D. number, PL year, and completion of curriculum components across the entire 3 years of the project. Table 6 contains a summary of the percentage of residents who started and completed each module by year, and by class. The greatest number of residents completed modules one through three, representing the first year of the curriculum, as would be expected. Due to difficulties with resident schedules, sick days, snow days, etc., we faced a constant challenge trying to move each resident through each component of each module in each year: the schedule was too tight, too inflexible. We developed a coding system for the data so that we could input reasons for missed visits and identify any cases of abuse of the system. After realizing that all of the residents would face difficulty finishing the curriculum, we conceded that the schedule as written was unworkable to a great extent, and in the final year of the program restructured the curriculum to better accommodate these challenges. We built-in time for sick days and snow days, interspersed through the modules, and while there were still instances when a resident moved into a module without completing the previous module, the occurrences were fewer. The percentages of residents who began and then completed each module is discussed further in objective 3.2, "Evaluate Program Status," and can also be seen on table 6.

Pre/Post Tests. These were given at the beginning and end of each module. When the project was in its infancy, the residents completed post tests, but not pre tests, so comparisons cannot be determined from that period. Additionally, as alluded to in the above paragraph, there were times when residents moved into a module, even though the previous module had not been completed. When this occurred, sometimes the post test was forgotten or neglected. Therefore, some residents completed pre tests for some modules, but not post tests. There are also instances later in the project were posts tests were completed, but not pre tests. This is difficult to explain, but fortunately did not occur with great frequency. It can be seen from the table that residents entered and left the curriculum at various times. For those whom we knew would spend an abbreviated amount of time with us, we tailored their schedule to allow for individual preferences, and for coverage of important components. In addition, because of their abbreviated time in this rotation (e.g. one or two years rather than three) they were allowed flexibility in the curriculum; they completed portions of the modules but not always all of it. This meant some residents only did one experience (rather than three or four) in a module. If they were not given a didactic session, they were not given a pre or post-test on the material. In the final year of the project the pre and post tests were restructured along with the rest of the curriculum. These tests were changed from open-ended, knowledge based, questions to simple comfort level questions that were rated on a 1-5 Likart Scale. As described previously, this was done to accommodate complaints from the residents on time requirements for the open ended tests, and also on time constraints for the didactic sessions themselves. Detailed discussion on pre and post test scores on a module by module basis can be found in objective 3.1: Evaluate Program Status.

Self-Evaluations. Residents were asked to rate themselves on a number of concepts during module experiential sessions. The concepts were devised to give three separate summary scores. These were: (1) reported opportunity to observe or use practices learned in the didactic sessions, (2) reported increased knowledge of the practices as a result of the visit, and (3) reported feeling satisfied with the visit. Scores from two statements on the self-evaluations were also pulled, "this visit was beneficial to me as a physician," and "overall, I was satisfied with the experience and knowledge gained from this visit." Table 9 contains a summary of these broken down by PL, module, and component. Table 10 is a compilation of all residents combined. The vast majority of residents affirmed that the competencies afforded them the opportunity to observe the practices that were reviewed in the didactic session and increase their knowledge as physicians. The vast majority of them also reported high satisfaction with the component visits and agreed that the visits were beneficial. Formative evaluation was always completed by the Project Coordinator. As the self-evaluations were handed in, they were reviewed immediately. The raw data was never changed, thus, the negative feedback is reflected in the data output. Indicated problems were addressed by the Project Coordinator or the Medical Consultant in a timely fashion. With this in mind, the data was reviewed for analysis. Of 292 scores for resident self evaluations, fully 286 (97%) score 85 and above. When all physician levels were combined, only 2 scores were less than 85. These were a score of 82 in the second component of the Family Centered Care module, a home visit with a continuity clinic patient, and a score of 82 in the third component of the Communication Skills and Team Participation module, which involved an observation of a team meeting in a child's school.

Preceptor Evaluations. The preceptors were asked to rate the residents on experiential visits for measures. The rating forms were summarized across the following concepts: (1) the resident used the didactic information, (2) the resident's general performance and (3) this was a beneficial experience for the preceptor; and statements: (1) the resident demonstrated appropriate professional behavior, and (2) as a preceptor, I was satisfied with the quality of the resident. Tables 11 &12 contain a summary of preceptor ratings by PL, module, and session. The picture is one of overall satisfaction with the project. Most preceptors were pleased with the residents' performance, and they generally reported benefit for themselves for having interacted with the resident. Again, formative evaluation applies. The preceptor evaluations for the 3 year period are uniformly high with few exceptions. The areas of exception are a specialty clinic visit in the Family Centered Care module, with a score of 77%, a specialty clinic visit in the Special Education module with a score of 63%, and a specialty clinic visit in the Role of Other Professionals module with a score of 67%. The question referred to involves the resident's use of the didactic material during the visit. Since most of the preceptors did not (and were not meant to) attend didactic sessions, this question was confusing, and so it was removed from the preceptor's evaluation form in the final year of the project. The other area reporting scores in the lower range are questions regarding whether the experience was beneficial to the preceptor. There are lower scores in the agency administrator interview component of the Interagency Collaboration module, and in the observation of a legislative hearing component of the Advocacy and Responsibility module. Since these involved discussions with high level, highly knowledgeable, individuals its not too surprising that these individuals didn't benefit from their interaction with the resident. The resident, however, benefited greatly, as can been seen in the resident self evaluations.

The preceptor evaluations were further broken down to enable us to view the ratings of parent and educator preceptors. There were 229 parent and educator evaluations which is 49.9% of the total of preceptor evaluations. These were uniformly positive, as can be seen in table 11. Parents rated the resident's general performance at 99.6%, and educators rated it at 97.4%. Parents rated the overall resident quality at 100%, while educators rated it at 98.4%. Parents said they benefited from the interaction 96.8% of the time, and educators said they benefited from the interaction 93.3% of the time.

Form B for the resident's continuity clinic patient visits were all regarded as positive. Please see Table 13 for comments made on these forms.

Module and Didactic Session Consumer Satisfaction. Lastly, the residents rated each didactic session and each module according to their satisfaction. Session satisfaction for the didactics were uniformly positive, with means above 4.25 for each question across all didactics, and means above 4.5 for each didactic across all modules. There were also comments written by residents on the benefits of the didactic sessions. The residents stated many different benefits, for example, one resident said the Family Centered Care Didactic helped her/him to, "view the patient as a whole including seeing the social and family perspective and not only the medical illness." Another resident spoke about the Early Intervention didactic session when s/he said that the session, "increased my knowledge about available services and taught me my role as a PCP." One resident commented in the 'add or omit' section that the session seemed too long, yet another resident felt s/he needed more time. This is a perfect example of how adult learning needs to be tailored to the individual to make it meaningful. Another resident, "thought this format was very helpful in that it used [his/her] experiences to expand into the goals/objectives of the session." Please see Appendix S for a listing of these comments by physician level and module. This list includes both benefits that the residents felt about the didactic sessions and what they would have added to or omitted from the session.

The module satisfactions had similar trends, but there were some lower scores for 3 questions in particular. These questions were about the quality of the readings, the methods and techniques, and the audio visuals used in the module. All of these issues were addressed in the 1999 restructuring of the curriculum, and resident comments in the closure sessions (discussed in the impact section of this report) were uniformly positive regarding the changes. It is important to realize that even these 3 questions had scores of 3.6 or higher, so they were still well within the positive range. The remainder of the questions (across all modules) rated 4.0 or above on a 5.0 Likart Scale. Resident comments about the modules are equally as remarkable as the comments about the didactics. One resident commented that the module Family Centered Care helped him/her gain, "a better understanding of the needs of the patient and his/her family outside the hospital/clinic environment and gained an appreciation for the sometimes overwhelming nature of the doctor's visit" (Appendix S).

The number of self and preceptor evaluations was always less than desired, and clearly, there was a difference in opinion about the importance of data between the Division and the residents and preceptors. Over the course of the 3 years of the project, there were many phone calls and letter reminders made to both the residents and the preceptors to return the forms.

Seminar Satisfaction. As a function of attending the evening seminar series, consumer satisfaction questionnaires were completed for each seminar. In general, these indicated satisfaction with each of the seminars. The data are on Table 3 and the seminars are further discussed in activity 2.4.

Medical Integration. We replaced our first year Medical Consultant with Sally Rosengren, MD, who then resigned during the second year. Dr. Eileen Fisk joined the Division in June, 1999 as Medical Consultant to the project. She remained with the project until the end. The Medical Consultant's responsibilities included conducting a biannual debriefing with each resident to obtain feedback on all areas of the curriculum, inquire about the resident integration of the project's content into their ongoing residency program and answer any questions. Dr. Mark Greenstein continued with the debriefing sessions until September 1999 when they were discontinued. The debriefing sessions were audio taped and then transcribed. The transcriptions provided some qualitative data that was coded and then entered into a debriefing summary (see Appendix I). There was no data collected in year one. Eighteen debriefing transcriptions were coded and used to produce the summary. They revealed that the residents applied the information they had learned to their practice, gave both positive and negative feedback regarding different parts of the curriculum, and identified barriers and needs, as evidenced in the summary.

In the third year of the project, the debriefing session was reinstated by Dr. Fisk for those third year residents who were graduating from the program. The goal was to review the resident's overall knowledge and impression of the curriculum. A sample of this closure session form can be found in appendix T. All 13 graduating residents, who had followed the typical residency schedule, were interviewed during their final block of the Children with Disabilities rotation. A detailed discussion of the information gathered can be found in the "Impact" section of this report.

National Recognition. The Project Director and the Residency Director At Connecticut Children's Medical Center presented two workshops on April 30, 1998, "Teaching Pediatric Residents to Care for Children with Disabilities: Putting it into Action" and "The Recruitment Process: A Panel" at the Association of Pediatric Program Directors Conference in New Orleans. The feedback from this conference was entirely verbal. It encompassed two main themes: (1) why isn't there more data and (2) can we get a copy of the curriculum? The Project Director, Project Coordinator and the Residency Program Director at Connecticut Children's Medical Center presented again at the Association of Pediatric Program Directors Conference in San

Francisco on April 30, 1999. The name of the workshop “Curriculum to Teach Residents to Care for Children with Disabilities III: Evidence of Effectiveness.” The presentation was in 3 parts: the first was an overview of the curriculum, presented by the Project Coordinator; the second, a summary of the data that had been collected up until that time, presented by the Project Director; and the third, a presentation by the Project Co-Director (who is also the UCONN Pediatric Residency Program Director) on how to fit this type of curriculum into the already full residency program schedule. Questions raised afterwards were based mostly on concerns about the difficulty of scheduling a longitudinal rotation that spans over 3 years, and also on the difficulty of obtaining funding to support it.

The curriculum was distributed in draft form to all of the people who requested it. Included with the curriculum was an evaluation form, asking for specific feedback on each module. Unfortunately, only one person ever returned the evaluation form.

This program was recognized by the Hartford Courant in an article called, “Linking Up For Students,” written by Warren Woodberry, Jr. The article speaks of the collaboration between the Rocky Hill School System and the UCONN Pediatric Residency Program through the Children With Disabilities Rotation. Please see Appendix U for a copy of this article.

Table 1

Outreach To Community Programs

Specialty Clinics in Project/Outreach to New Programs

Lynn Behrmann on daycare centers	March 24, 1999
Joanne Stevens on specialty clinics: -Cranialfacial -Cystic Fibrosis	March 23, 1999
Jim Loomis on specialty clinics	March 23, 1999
Carolyn Cartland on specialty clinics: -Cerebral Palsy -Mylomeningocele -Muscle Disease -Diabetes	March 23, 1999
Trinity College Community Child Center	September 22, 1998
Barbara Draheim on Muscle Disease and Mylomeningocele Specialty Clinics	September 15, 1998
Jim Loomis on all Specialty Clinics	September 2, 1998
Cranial Facial Specialty Clinic	June 20, 1998
Jim Loomis on Team Meetings	June 1, 1998
NICU Follow-Up Clinic	April, 7 1998
Kinsella Daycare	April 1, 1998
Jim Loomis on Specialty Clinics	March 27, 1998
Carolyn Cartland on Specialty Clinics	March 27, 1998
Thurman Milner Elementary School	March 26, 1998
UCONN Day Care Center	December 12, 1997
Child Development Center	December 4, 1997
Adaptive Equipment Clinic	December 4, 1997
CCMC Rehabilitation Department	December 4, 1997
Cerebral Palsy Clinic, Muscle Disease Clinic	December 2, 1997
NICU Follow-Up Clinic	November 25, 1997
Hospital For Special Care	November 19, 1997
First Church Nursery School	November 11, 1997

Table 1 (continued)

Early Connections	November 3, 1997
The Cardiology Department at CCMC	November , 1997
East Hartford Birth to Three	October 23, 1997
The Pulmonary Department at CCMC -BPD Clinic -Muscle Disease -Cystic Fibrosis -General Pulmonary	October 1, 1997
Simsbury School System	September 11, 1997
Carolyn Cartland, M.S.W. -Cerebral Palsy -Muscle Respiratory -Myelomeningocel	September 10, 1997
Neurology Department at CCMC	September 9, 1997
Rehabilitation Department at CCMC	September 9, 1997
High Hopes	September 5, 1997
Speech and Audiology Department at CCMC	September 4, 1997
The Burgdorf Clinic, Dr. David Black	September 4, 1997
Saint Frances Hospital, Dr. Carl Orkin	September 4, 1997
Genetics Department at CCMC	September 4, 1997

Table 1 (continued)

Outreach To New Programs:

Mary Laliberte on Hematology and Oncology specialty clinic	March 25, 1999
Bolton School System	October 23, 1998
Canton School System	October 16, 1998
Bloomfield School System	October 14, 1998
Easter Seals Day Care	September 21, 1998
Canton School System	September 10, 1998
Diabetes Specialty Clinic	September 1, 1998
The Learning Center at the American School for the Deaf	September 1, 1998
New Britain General Hospital Child Care Center	September 1, 1998
Rocky Hill School System	August 31, 1998
Bloomfield School System	August 31, 1998
East Granby School System	August 31, 1998
Capitol Child Development Center, Inc.	July 9, 1998
Molly Cole on Family Participation	June 24, 1998
Uconn Child Development Laboratory	June 21, 1998
Bright Horizons	June 17, 1998
The Darse School	June 17, 1998
Molly Cole on Interagency Interview	April 16, 1998
Jane Bisantz Associates follow up	April 16, 1998
Project Interact	April 6, 1998
Jane Bisantz Associates	April 2, 1998
Molly Cole on School Systems	April 1, 1998
Molly Cole on Families	April 1, 1998

Table 1 (continued)

Deb Richards on Early Intervention Programs	April 1, 1998
Stepping Stones Birth To Three Program	November 24, 1997
Avon Public School System	November 24, 1997
Bright Beginnings Preschool	November 3, 1997
Griswald Middle School	October 30, 1997
Farmington School System	September 18, 1997

Table 2

Resident Demographic Information (N = 92)

January 1, 1997 – June 24, 2000

Physician Year	Number of Residents		
	Pediatrics	Medicine/Pediatrics	*total
PL-1	53	8	61
PL-2	55	6	61
PL-3	54	4	58
PL-4	0	2	2
Early Exit	5	0	5
By Class			total
2002			15
2001			15
2000 (includes 6 residents on individualized schedules)			19
1999			11
1998			13
1997			14
Early Exit			5
Age	**number**	**percentage**	
25-29 years	57	62	
30-34 years	21	23	
35-39 years	6	6.5	
40-44 years	0	0	
45-49 years	1	1.1	
Missing	7	7.6	
Race or Ethnic Group			
African American	1	1.1	
Asian	5	5.4	
Caucasian	61	66.3	
Haitian	1	1.1	
Indian	4	4.3	
Latino	3	3.3	
Other	3	3.3	
Unknown	14	15.2	
Marital Status			
Single	38	41.3	
Married	44	47.8	
Unknown	10	11.0	

*Greater than 100% because each physician on a typical schedule must complete 3-4 years of residency training; therefore, each physician can be counted from 1-4 times.

Country of Origin		
Arabia	1	1.1
England	2	2.2
France	1	1.1
Germany	1	1.1
Guyana	1	1.1
Haiti	1	1.1
Hong Kong	1	1.1
Iceland	6	6.5
India	8	8.7
Mexico	1	1.1
Philippines	1	1.1
Poland	1	1.1
Taiwan	1	1.1
United States of America	60	65.2
Uruguay	1	1.1
Unknown	5	5.4

Table 3

SEMINAR CONSUMER SATISFACTION COMPARISON
All* Responses Compared by Mean & Standard Deviation

Seminar Titles & Dates	Time was well organized.	The information is relevant and can be applied to my situation.	Adequate illustrations and examples were used during presentations.	The presenters were well prepared and organized.	The presenters were knowledgeable in the subject.
How to Give Bad News (11/13/97)	4.58 (0.58)	4.81 (0.40)	4.77 (0.43)	4.81 (0.40)	4.89 (0.33)
Ethical Aspects of Decision Making (1/29/98)	4.56 (0.63)	4.63 (0.72)	4.75 (0.58)	4.94 (0.25)	5.00 (0.00)
Using the Legislative Process (3/19/98)	4.63 (0.62)	4.48 (0.64)	4.67 (0.82)	4.69 (0.48)	4.75 (0.58)
Hospice and the Dying Child (5/26/98)	4.01 (0.59)	4.38 (0.73)	4.33 (1.04)	4.62 (0.49)	4.68 (0.55)
The Impact of Domestic Abuse on Children (9/24/98)	4.06 (0.83)	4.62 (0.55)	4.32 (0.64)	4.41 (0.61)	4.62 (0.55)
The Importance of Hope in the Lives of Children With Special Needs (11/3/98)				4.69 (0.54)	4.78 (0.42)
Learning and Using the Legislative Process (2/4/99)	3.65 (1.23)	4.26 (0.69)	4.09 (1.20)	4.26 (0.92)	4.44 (0.95)
Coordinating Resources in Our Community (4/15/99)			4.42 (0.52)	4.42 (0.52)	4.67 (0.49)
Real Pediatricians Provide Primary Care Medical home for Children With Chronic Illness (9/2/99)	3.65 (1.09)	4.25 (1.07)	3.95 (1.16)	4.38 (1.07)	4.48 (1.21)
How to Give Bad News (12/7/99)	4.47 (0.57)	4.87 (0.43)	4.63 (0.62)	4.71 (0.46)	4.87 (0.35)
Pediatric Mental Health: Where Are We Going? (3/8/00)	2.95 (1.35)	2.95 (1.43)	3.32 (1.29)	3.95 (0.71)	4.16 (0.69)
A Millionaire's Jeopardy (5/25/00)	4.30 (0.82)	4.20 (0.63)	3.80 (1.03)	4.60 (0.52)	4.90 (0.32)

*residents and non-residents combined

Table 3 (continued)

SEMINAR CONSUMER SATISFACTION COMPARISON
All* Responses Compared by Mean & Standard Deviation

Seminar Titles	The presenters used a variety of activities that corresponded with the content.	The presenters were easy to listen to.	The presenters valued our input.	Overall satisfaction.
How to Give Bad News (11/13/97)	4.52 (0.59)	4.85 (0.37)	4.85 (0.46)	4.78 (0.37)
Ethical Aspects of Decision Making (1/29/98)	4.31 (0.70)	4.69 (0.48)	4.75 (0.48)	4.78 (0.37)
Using the Legislative Process (3/19/98)	4.50 (0.73)	4.75 (0.48)	4.63 (0.62)	4.72 (0.52)
Hospice and the Dying Child (5/26/98)	3.89 (0.89)	4.31 (0.71)	4.41 (0.57)	4.38 (0.49)
The Impact of Domestic Abuse on Children (9/24/98)	4.00 (0.82)	4.47 (0.51)	4.29 (0.58)	4.47 (0.56)
The Importance of Hope in the Lives of Children With Special Needs (11/3/1998)	4.52 (0.63)	4.54 (0.50)	4.61 (0.62)	4.53 (0.62)
Learning and Using the Legislative Process (2/4/99)	4.30 (1.06)	4.41 (0.96)	4.48 (0.98)	4.26 (0.81)
Coordinating Resources in Our Community (4/15/99)	3.67 (0.65)	4.25 (0.62)	4.33 (0.78)	4.50 (0.52)
Real Pediatricians Provide Primary Care Medical home for Children With Chronic Illness (9/2/99)	3.81 (1.25)	4.00 (1.14)	4.25 (1.16)	4.05 (1.12)
How to Give Bad News (12/7/99)	4.77 (0.43)	4.65 (0.55)	4.60 (0.56)	4.63 (0.49)
Pediatric Mental Health: Where Are We Going? (3/8/00)	2.79 (1.13)	3.16 (1.39)	4.05 (2.04)	3.05 (1.31)
A Millionaire's Jeopardy (5/25/00)	4.80 (0.42)	4.70 (0.48)	4.70 (0.48)	4.70 (0.48)

*residents and non-residents combined

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: June 1996 - December 1996

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	17	✓										
1	18	✓	✓			✓		✓	✓			
1	19	✓	✓	✓		✓						
1	21	✓		✓	✓	✓						
1	22	✓			✓							
1	23	✓			✓	✓						
1	24	✓	✓			✓						
1	25	✓	✓									
1	27	✓	✓		✓							✓
1	28	✓	✓		✓	✓						
1	29	✓				✓						
1	30	✓		✓								✓
1	31	✓	✓									
1	42	✓										

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	17									
1	18									
1	19									
1	21									
1	22									
1	23									
1	24									
1	25									
1	27									
1	28									
1	29									
1	30									
1	31									
1	42									

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	17											
1	18											
1	19											
1	21											
1	22											
1	23											
1	24											
1	25											
1	27											
1	28											
1	29											
1	30											
1	31											
1	42											

RESIDENTS' PROGRESS IN CURRICULUM BY TIME BLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	32	✓	✓	✓	✓	✓						✓
2	33	✓	✓		✓	✓						
2	34	✓	✓			✓						
2	35	✓		✓	✓	✓	✓					
2	36	✓			✓	✓		✓				
2	37	✓	✓						✓			
2	38	✓	✓		✓	✓			✓			
2	39	✓			✓							
2	40	✓	✓			✓		✓	✓			
2	41	✓	✓		✓							✓
2	42					✓		✓	✓			
2	43	✓	✓		✓	✓						
2	55	✓	✓		✓	✓						

RESIDENTS' PROGRESS IN CURRICULUM BY TIME BLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	32									
2	33									
2	34									
2	35									
2	36									
2	37									
2	38									
2	39									
2	40									
2	41									
2	42									
2	43									
2	55									

RESIDENTS' PROGRESS IN CURRICULUM BY TIME BLOCK AND PHYSICIAN LEVEL
DATES: June 1996 - December 1996

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	32											
2	33											
2	34											
2	35											
2	36											
2	37											
2	38											
2	39											
2	40											
2	41											
2	42											
2	43											
2	55											

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	51	✓	✓									
3	52	✓	✓		✓	✓						
3	53					✓		✓		✓		
3	54		✓	✓	✓	✓			✓			
3	56	✓		✓	✓	✓			✓		✓	
3	57			✓		✓		✓				
3	58	✓	✓		✓	✓			✓	✓		
3	59	✓	✓		✓			✓				
3	60			✓		✓		✓	✓	✓		
3	61				✓	✓	✓	✓		✓		✓
3	62	✓	✓									
3	63			✓	✓	✓	✓		✓			
3	64		✓			✓		✓	✓	✓		
3	65	✓		✓	✓							

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	51	✓								
3	52									
3	53									
3	54									
3	56									
3	57	✓	✓							
3	58									
3	59									
3	60									
3	61	✓								
3	62									
3	63									
3	64									
3	65									

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: June 1996 - December 1996

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	51											
3	52											
3	53											
3	54											
3	56											
3	57											
3	58											
3	59											
3	60											
3	61											
3	62											
3	63											
3	64											
3	65											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

PL	Resident ID	Family-Centered Care				Early Intervention			Special Education			
		D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	2	✓										
1	17		✓		✓	✓			✓	✓		✓
1	18			✓			✓					
1	19								✓	✓		✓
1	21						✓		✓	✓		✓
1	22					✓			✓	✓		✓
1	23		✓				✓	✓	✓	✓		✓
1	24								✓			
1	25					✓			✓	✓		
1	27					✓	✓	✓	✓	✓		
1	28								✓			
1	30					✓		✓	✓	✓	✓	
1	31					✓		✓	✓	✓		

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	2									
1	17									
1	18									
1	19									
1	21									
1	22	✓								
1	23									
1	24									
1	25									
1	27									
1	28									
1	30									
1	31									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	2											
1	17											
1	18											
1	19											
1	21											
1	22											
1	23											
1	24											
1	25											
1	27											
1	28											
1	30											
1	31											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	29		✓		✓				✓			
2	32							✓	✓			
2	33							✓	✓	✓		✓
2	34			✓				✓		✓		✓
2	35								✓		✓	
2	36								✓	✓		
2	37				✓					✓		
2	38									✓		
2	39					✓			✓	✓		✓
2	40											
2	41					✓	✓	✓	✓	✓		
2	43								✓	✓		
2	55							✓	✓			

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	29									
2	32			✓		✓				
2	33	✓								
2	34				✓					
2	35									
2	36									
2	37	✓								
2	38									
2	39	✓								
2	40		✓							
2	41				✓					
2	43									
2	55	✓		✓		✓				

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	29											
2	32											
2	33											
2	34											
2	35											
2	36											
2	37											
2	38											
2	39											
2	40											
2	41											
2	43											
2	55											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	51					✓		✓	✓	✓		
3	52			✓					✓	✓		
3	53				✓							
3	54											✓
3	56									✓		
3	57											
3	58											✓
3	59								✓			
3	60											
3	61											
3	62				✓	✓			✓	✓		
3	63											
3	64											✓
3	65					✓		✓	✓	✓		

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: January 1997 - June 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	51									
3	52	✓						✓		
3	53	✓				✓				
3	54					✓		✓		
3	56	✓	✓					✓		
3	57					✓				
3	58									
3	59	✓				✓				
3	60	✓				✓				✓
3	61		✓							
3	62	✓				✓				
3	63	✓	✓			✓				
3	64	✓				✓				
3	65	✓				✓				

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1997 - June 1997

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	51											
3	52											
3	53								✓			
3	54								✓			
3	56											
3	57											
3	58								✓			
3	59								✓			
3	60								✓			
3	61											
3	62											
3	63											
3	64											
3	65											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	1	✓	✓	✓	✓							
1	2		✓		✓	✓						
1	3	✓	✓	✓	✓	✓	✓					
1	4	✓	✓		✓	✓						
1	5	✓										
1	7	✓										
1	8	✓	✓	✓	✓	✓					✓	✓
1	10	✓	✓	✓		✓						✓
1	11	✓	✓		✓	✓	✓					
1	12	✓	✓		✓							
1	13	✓	✓	✓	✓	✓		✓				
1	14	✓	✓	✓	✓							
1	15	✓	✓		✓	✓						
1	16	✓	✓		✓							

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	1									
1	2									
1	3									
1	4									
1	5									
1	7									
1	8									
1	10									
1	11									
1	12									
1	13									
1	14									
1	15									
1	16									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	1											
1	2											
1	3											
1	4											
1	5											
1	7											
1	8								✓			
1	10											
1	11											
1	12											
1	13											
1	14											
1	15											
1	16											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	18				✓						✓	✓
2	19				✓		✓					
2	21											
2	22							✓				
2	23			✓								
2	24			✓	✓		✓	✓		✓		✓
2	25						✓					
2	27											
2	28			✓			✓			✓		✓
2	29						✓					
2	30				✓							
2	31			✓							✓	
2	42		✓		✓							

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	18	✓	✓							
2	19	✓		✓						
2	21	✓		✓						
2	22									
2	23	✓		✓						
2	24									
2	25									
2	27	✓		✓						
2	28	✓	✓				✓			
2	29									
2	30	✓	✓				✓			
2	31	✓								
2	42									✓

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	32						✓					
3	33						✓					
3	34								✓			
3	35									✓		✓
3	36		✓				✓					
3	37											
3	38											
3	39											
3	40									✓		
3	41			✓								
3	42			✓								
3	43											✓
3	44	✓			✓	✓			✓	✓		
3	53								✓			

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	32	✓	✓							
3	33									
3	34	✓		✓						
3	35			✓	✓					
3	36									
3	37			✓		✓				
3	38			✓						
3	39		✓							
3	40	✓		✓						
3	41									
3	42									
3	43	✓								
3	44		✓							
3	53									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1997 - December 1997

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	32											
3	33											
3	34											
3	35											
3	36											
3	37											
3	38								✓			
3	39											
3	40											
3	41											
3	42											
3	43											
3	44											
3	53											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	1					✓	✓	✓	✓	✓		
1	3								✓			✓
1	4			✓			✓	✓	✓	✓		
1	5		✓	✓		✓	✓		✓	✓		
1	7		✓	✓	✓	✓			✓	✓	✓	✓
1	8						✓	✓	✓			
1	10						✓	✓	✓	✓		
1	11							✓	✓	✓		✓
1	12			✓		✓		✓	✓		✓	
1	13						✓		✓	✓		
1	14					✓	✓	✓	✓	✓	✓	
1	15							✓	✓	✓		
1	16					✓	✓	✓	✓	✓		

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	1									
1	3									
1	4									
1	5									
1	7									
1	8									
1	10	✓								
1	11									
1	12									
1	13							✓		
1	14	✓								
1	15									
1	16									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	1											
1	3											
1	4											
1	5											
1	7											
1	8											
1	10											
1	11											
1	12								✓			
1	13											
1	14											
1	15											
1	16											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	2			✓			✓		✓	✓		✓
2	17											
2	18											
2	19											
2	21											
2	22		✓				✓					
2	23											
2	24										✓	
2	25							✓			✓	✓
2	27											
2	28											
2	29			✓								
2	30						✓					
2	31				✓		✓					✓

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	2									
2	17	✓		✓	✓					
2	18			✓						
2	19				✓				✓	✓
2	21		✓		✓	✓		✓		
2	22		✓	✓	✓			✓	✓	
2	23		✓		✓		✓	✓		
2	24	✓		✓						✓
2	25	✓	✓							
2	27					✓				
2	28			✓	✓					
2	29									
2	30			✓	✓			✓		
2	31		✓	✓	✓					

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	2											
2	17								✓			
2	18								✓			
2	19											
2	21											
2	22	✓										
2	23	✓	✓									
2	24											
2	25											
2	27											
2	28											
2	29											
2	30											
2	31											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	29									✓		
3	32									✓	✓	
3	33											
3	34				✓						✓	
3	35		✓									
3	36											✓
3	37			✓								
3	38						✓	✓				
3	39											
3	40						✓					
3	41										✓	
3	42									✓		
3	43						✓					
3	44											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	29		✓	✓				✓		
3	32							✓		
3	33		✓	✓	✓			✓		
3	34		✓							
3	35									
3	36		✓	✓						
3	37							✓		
3	38		✓					✓		
3	39									
3	40									
3	41		✓	✓				✓		
3	42									
3	43			✓	✓					
3	44									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1998 - June 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	29											
3	32					✓			✓			
3	33			✓		✓						
3	34					✓			✓			
3	35								✓			
3	36					✓						
3	37					✓						
3	38	✓										
3	39	✓				✓	✓					
3	40					✓	✓					
3	41											
3	42											
3	43	✓				✓						
3	44					✓						

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	68	✓	✓		✓	✓						
1	69	✓	✓			✓	✓	✓				
1	70	✓	✓		✓	✓						✓
1	71	✓	✓		✓	✓	✓	✓	✓			
1	72	✓	✓									
1	73	✓	✓		✓	✓			✓			
1	74	✓	✓	✓		✓	✓		✓		✓	
1	78	✓	✓		✓	✓						
1	79	✓	✓			✓						
1	82	✓	✓		✓	✓		✓	✓			
1	83	✓			✓							✓
1	84	✓	✓		✓	✓						

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	68									
1	69									
1	70									
1	71									
1	72									
1	73			✓						
1	74									
1	78									
1	79									
1	82									
1	83				✓					
1	84									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	68											
1	69											
1	70											
1	71											
1	72											
1	73								✓			
1	74											
1	78											
1	79											
1	82											
1	83											
1	84											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	1											
2	2							✓				
2	3							✓		✓		
2	4											✓
2	5				✓							✓
2	7						✓	✓				
2	8									✓		
2	10											
2	11			✓								
2	12						✓			✓		✓
2	13											
2	14											✓
2	15			✓			✓					✓
2	16											
2	80	✓	✓		✓	✓						

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	1	✓								
2	2	✓	✓	✓	✓	✓		✓		
2	3	✓		✓	✓			✓		
2	4	✓	✓	✓	✓					
2	5	✓								
2	7					✓				
2	8									
2	10		✓	✓	✓	✓	✓	✓		
2	11	✓		✓	✓	✓				
2	12									
2	13	✓		✓		✓	✓			✓
2	14			✓	✓					
2	15	✓	✓							
2	16	✓	✓	✓		✓		✓		
2	80									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	1											
2	2											
2	3								✓			
2	4											
2	5											
2	7											
2	8											
2	10											
2	11											
2	12											
2	13											
2	14											
2	15								✓			
2	16											
2	80											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	17											
3	18											
3	19							✓				
3	22			✓								
3	23											
3	24											
3	28											
3	29											
3	30											
3	76	✓			✓							✓
3	81	✓			✓							

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: July 1998 - December 1998

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	17		✓					✓		
3	18									
3	19									
3	22									
3	23									
3	24		✓		✓			✓		
3	28									
3	29									
3	30									
3	76									
3	81		✓							

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1998 - December 1998

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	17	✓										
3	18	✓				✓						
3	19			✓					✓			
3	22		✓				✓		✓			
3	23					✓						
3	24	✓				✓			✓			
3	28	✓							✓			
3	29					✓						
3	30	✓										
3	76	✓				✓			✓			
3	81			✓								

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	67	✓	✓	✓	✓	✓		✓	✓	✓		✓
1	68			✓			✓		✓	✓		✓
1	69								✓	✓		✓
1	70						✓	✓	✓	✓		
1	71									✓		
1	72				✓	✓	✓	✓	✓	✓		
1	73						✓			✓		
1	74							✓		✓		✓
1	78			✓			✓		✓			✓
1	79			✓	✓		✓	✓	✓	✓	✓	✓
1	82						✓			✓	✓	✓
1	83		✓			✓	✓		✓			
1	84			✓			✓	✓	✓	✓		✓

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	67			✓						
1	68									
1	69									
1	70									
1	71	✓								
1	72									
1	73									
1	74	✓								
1	78									
1	79									
1	82	✓								
1	83									
1	84	✓			✓					

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	67											
1	68											
1	69											
1	70											
1	71											
1	72											
1	73											
1	74											
1	78											
1	79											
1	82											
1	83											
1	84								✓			

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	1										✓	✓
2	4											
2	5										✓	
2	7											
2	8											
2	10											
2	11										✓	
2	12											
2	13											✓
2	14											
2	16			✓							✓	
2	80						✓		✓	✓		

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	1		✓	✓	✓	✓	✓	✓		
2	4					✓		✓		
2	5			✓	✓	✓				
2	7	✓	✓	✓	✓					
2	8	✓		✓	✓	✓	✓	✓		
2	10								✓	
2	11		✓					✓		
2	12	✓	✓	✓						
2	13		✓		✓				✓	
2	14		✓			✓	✓	✓	✓	
2	16						✓			
2	80									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	1											
2	4						✓		✓			
2	5								✓			
2	7											
2	8											
2	10	✓		✓								
2	11											
2	12											
2	13											
2	14	✓										
2	16								✓			
2	80											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: January 1999 - June 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	2											
3	10											
3	11											
3	17											
3	18											
3	19											
3	22											
3	23											
3	24											
3	28										✓	
3	30											
3	31											
3	76											
3	81											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
3	2						✓			
3	10									
3	11									
3	17									
3	18							✓		
3	19									
3	22									
3	23									
3	24									
3	28							✓		
3	30									
3	31							✓		
3	76							✓		
3	81									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 1999 - June 1999

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	2	✓					✓		✓			
3	10					✓						
3	11	✓										
3	17					✓	✓					
3	18						✓	✓				
3	19				✓					✓	✓	✓
3	22				✓	✓		✓		✓	✓	✓
3	23			✓	✓			✓	✓	✓	✓	✓
3	24						✓					
3	28					✓						
3	30					✓			✓			
3	31	✓		✓		✓	✓					
3	76						✓	✓				
3	81	✓				✓	✓					

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	85	✓	✓		✓	✓			✓			✓
1	86	✓	✓		✓	✓	✓		✓			
1	87	✓	✓			✓						
1	88	✓	✓			✓						
1	89	✓	✓		✓	✓	✓		✓			✓
1	90	✓	✓		✓							
1	91	✓	✓		✓	✓	✓		✓			
1	93	✓	✓		✓	✓			✓			✓
1	94	✓	✓			✓						
1	95	✓	✓		✓	✓	✓	✓				
1	96	✓	✓		✓	✓	✓					
1	98	✓	✓		✓	✓						
1	99	✓	✓		✓							

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	85									
1	86									
1	87									
1	88									
1	89									
1	90									
1	91									
1	93									
1	94									
1	95									
1	96									
1	98									
1	99									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: July 1999 - December 1999

PL	Resident ID	Interagency Collaboration D	C2	C3	C4	Advocacy and Responsibility and Legislative Process D	C2	C3	C4	C5	C6	C7
1	85											
1	86											
1	87											
1	88											
1	89											
1	90											
1	91											
1	93											
1	94											
1	95											
1	96											
1	98											
1	99											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	67						✓				✓	
2	68											
2	69			✓	✓							
2	70			✓							✓	
2	71											✓
2	72			✓								✓
2	73			✓				✓			✓	✓
2	74											
2	78											
2	79											
2	82			✓								
2	83							✓				
2	84											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	67	✓	✓		✓	✓	✓			✓
2	68	✓		✓						
2	69	✓	✓	✓	✓	✓			✓	
2	70	✓		✓	✓					
2	71		✓	✓	✓	✓				
2	72	✓	✓	✓	✓					
2	73	✓			✓					
2	74		✓	✓	✓	✓	✓	✓		
2	78			✓						
2	79	✓	✓	✓	✓		✓			
2	82		✓	✓	✓	✓	✓			
2	83	✓	✓	✓		✓				
2	84		✓	✓		✓	✓	✓	✓	

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	67						✓					
2	68											
2	69											
2	70						✓					
2	71											
2	72											
2	73											
2	74	✓			✓							
2	78											
2	79											
2	82											
2	83	✓										
2	84											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	1											
3	2											
3	3											
3	4											
3	5											
3	7											
3	8											
3	10											
3	11											
3	12											
3	13											
3	14											
3	16											
3	31											
3	80											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

PL	Resident ID	Team-Based Service Models; Roles				Communication Skills and Team Participation				
		D	C2	C3	C4	D	C2	C3	C4	C5
3	1									
3	2									
3	3		✓							
3	4									
3	5		✓					✓	✓	
3	7									
3	8									
3	10									
3	11									
3	12				✓			✓		
3	13									
3	14									
3	16									
3	31									
3	80	✓	✓	✓						

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: July 1999 - December 1999

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	1	✓	✓	✓	✓							
3	2					✓						
3	3	✓					✓					
3	4	✓	✓	✓	✓	✓						
3	5	✓	✓	✓	✓					✓		
3	7	✓	✓	✓	✓	✓	✓	✓				
3	8	✓			✓	✓		✓		✓	✓	
3	10		✓					✓	✓			
3	11		✓									
3	12	✓	✓		✓					✓	✓	
3	13	✓	✓									
3	14		✓	✓	✓	✓	✓			✓		
3	16	✓			✓							
3	31		✓									
3	80											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
1	85						✓	✓		✓		
1	86			✓				✓		✓		✓
1	87				✓		✓	✓	✓	✓		✓
1	88				✓		✓	✓	✓	✓		✓
1	89			✓				✓		✓		
1	90					✓	✓	✓	✓	✓	✓	✓
1	91									✓	✓	
1	93			✓			✓	✓		✓	✓	
1	94			✓	✓		✓	✓	✓	✓	✓	✓
1	95			✓					✓			✓
1	96			✓					✓	✓		✓
1	98			✓			✓		✓	✓	✓	
1	99			✓		✓	✓	✓	✓	✓		✓

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
1	85	✓	✓							
1	86	✓								
1	87	✓		✓						
1	88	✓	✓							
1	89	✓			✓					
1	90	✓		✓						
1	91	✓	✓	✓						
1	93	✓								
1	94	✓			✓					
1	95	✓	✓		✓					
1	96	✓			✓					
1	98	✓								
1	99	✓								

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
1	85											
1	86											
1	87											
1	88											
1	89											
1	90											
1	91											
1	93											
1	94											
1	95											
1	96											
1	98											
1	99											

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
2	67											
2	68											
2	69										✓	
2	70											
2	71			✓								
2	72											
2	73											
2	74				✓							
2	78									✓	✓	
2	79											
2	82											
2	83									✓		
2	84										✓	

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Team-Based Service Models; Roles				Communication Skills and Team Participation				
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5
2	67							✓		
2	68		✓		✓	✓	✓	✓		
2	69						✓	✓		
2	70		✓			✓	✓	✓		
2	71						✓	✓		
2	72					✓				
2	73		✓			✓	✓	✓	✓	
2	74									
2	78		✓			✓				
2	79					✓			✓	
2	82							✓		
2	83						✓	✓		
2	84									

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
2	67	✓			✓							
2	68	✓	✓	✓								
2	69	✓	✓									
2	70	✓	✓									
2	71	✓										
2	72											
2	73	✓										
2	74											
2	78											
2	79	✓	✓									
2	82	✓	✓		✓							
2	83											
2	84	✓	✓			✓						

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

DATES: January 2000 - June 2000

		Family-Centered Care				Early Intervention			Special Education			
PL	Resident ID	D	C2	C3	C4	D	C2	C3	D	C2	C3	C4
3	1											
3	4											
3	5											
3	7											
3	8											
3	10											
3	11											
3	12											
3	13											
3	14											
3	16											✓
3	80											✓

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

PL	Resident ID	Team-Based Service Models; Roles				Communication Skills and Team Participation				
		D	C2	C3	C4	D	C2	C3	C4	C5
3	1									
3	4									
3	5									
3	7									
3	8									
3	10									
3	11									
3	12									
3	13									
3	14									
3	16									
3	80					✓	✓			

TABLE 4

RESIDENTS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL
DATES: January 2000 - June 2000

		Interagency Collaboration				Advocacy and Responsibility and Legislative Process						
PL	Resident ID	D	C2	C3	C4	D	C2	C3	C4	C5	C6	C7
3	1					✓	✓		✓	✓	✓	✓
3	4									✓	✓	✓
3	5						✓					✓
3	7									✓	✓	✓
3	8		✓				✓					✓
3	10				✓					✓	✓	✓
3	11			✓	✓	✓	✓			✓	✓	✓
3	12			✓		✓	✓					✓
3	13				✓	✓	✓			✓	✓	✓
3	14							✓	✓		✓	✓
3	16			✓		✓					✓	✓
3	80											

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Family-Centered Care				Early Intervention		
Time Block	PL	Resident ID	D	C2	C3	Full Curr.	D	C2	Full Curr.
Jan 1997 - Jun 1997									
	1	20			✓				
	1	26					✓		✓
Jul 1997 - Dec 1997									
	1	6	✓	✓		✓			
	1	9	✓	✓		✓	✓		
	2	20							
	2	26				✓			
Jan 1998 - Jun 1998									
	1	6					✓	✓	
Jul 1998 - Dec 1998									
	1	75	✓	✓		✓	✓	✓	
	1	77	✓		✓	✓	✓	✓	

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Special Education			
Time Block	PL	Resident ID	D	C2	C3	Full Curr.
Jan 1997 - Jun 1997						
	1	20	✓			
	1	26	✓			
Jul 1997 - Dec 1997						
	1	6				
	1	9				
	2	20				✓
	2	26				
Jan 1998 - Jun 1998						
	1	6				
Jul 1998 - Dec 1998						
	1	75				
	1	77				

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Team-Based Service Models; Roles				Communication Skills and Team Participation			
Time Block	PL	Resident ID	D	C2	C3	Full Curr.	D	C2	C3	Full Curr.
Jan 1997 - Jun 1997										
	1	20								
	1	26								
Jul 1997 - Dec 1997										
	1	6								
	1	9								
	2	20	✓							
	2	26							✓	
Jan 1998 - Jun 1998										
	1	6								
Jul 1998 - Dec 1998										
	1	75								
	1	77								

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

Time Block	PL	Resident ID	Interagency Collaboration				Advocacy and Responsibility and Legislative Process			
			D	C2	C3	Full Curr.	D	C2	C3	Full Curr.
Jan 1997 - Jun 1997										
	1	20								
	1	26								
Jul 1997 - Dec 1997										
	1	6								
	1	9								
	2	20								
	2	26								
Jan 1998 - Jun 1998										
	1	6								
Jul 1998 - Dec 1998										
	1	75								
	1	77								

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Family-Centered Care				Early Intervention		
Time Block	PL	Resident ID	D	C2	C3	Full Curr.	D	C2	Full Curr.
Jan 1999 - Jun 1999									
	2	6							✓
	2	9							
	3	20						✓	
	3	26							
Jul 1999 - Dec 1999									
	1	92	✓	✓		✓	✓	✓	
	1	97	✓	✓		✓			
	3	6			✓				
	3	9							
	4	20							
	4	26							
Jan 2000 - Jun 2000									
	1	97					✓	✓	
	2	75							
	2	77							
	3	6							
	3	9			✓			✓	
	4	20							
	4	26							

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Special Education			
Time Block	PL	Resident ID	D	C2	C3	Full Curr.
Jan 1999 - Jun 1999						
	2	6	✓			
	2	9	✓	✓		
	3	20				
	3	26				
Jul 1999 - Dec 1999						
	1	92				✓
	1	97				
	3	6		✓	✓	
	3	9				
	4	20				
	4	26				
Jan 2000 - Jun 2000						
	1	97				
	2	75	✓	✓		
	2	77	✓		✓	✓
	3	6				
	3	9				
	4	20				
	4	26				

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

			Team-Based Service Models; Roles				Communication Skills and Team Participation			
Time Block	PL	Resident ID	D	C2	C3	Full Curr.	D	C2	C3	Full Curr.
Jan 1999 - Jun 1999										
	2	6	✓							
	2	9								
	3	20								
	3	26		✓						
Jul 1999 - Dec 1999										
	1	92								
	1	97								
	3	6			✓					
	3	9	✓	✓						
	4	20								
	4	26								
Jan 2000 - Jun 2000										
	1	97								
	2	75								
	2	77							✓	
	3	6		✓					✓	
	3	9			✓					
	4	20							✓	
	4	26								

TABLE 5

MED-PEDS' PROGRESS IN CURRICULUM BY TIMEBLOCK AND PHYSICIAN LEVEL

Time Block	PL	Resident ID	Interagency Collaboration D	Interagency Collaboration C2	Interagency Collaboration C3	Interagency Collaboration Full Curr.	Advocacy and Responsibility and Legislative Process D	Advocacy and Responsibility and Legislative Process C2	Advocacy and Responsibility and Legislative Process C3	Advocacy and Responsibility and Legislative Process Full Curr.
Jan 1999 - Jun 1999										
	2	6								
	2	9								
	3	20								
	3	26						✓	✓	✓
Jul 1999 - Dec 1999										
	1	92								
	1	97								
	3	6								
	3	9								
	4	20			✓	✓				
	4	26	✓			✓				
Jan 2000 - Jun 2000										
	1	97								
	2	75								
	2	77								
	3	6	✓							
	3	9								
	4	20								
	4	26								

Table 6: Resident's Progress Through the Curriculum by Module

Module	Class '02 (n=15)		Class '01 (n=15)		Class '00 (n=19*)		Class '99 (n=11)		Class '98 (n=13)		Class '97 (n=14)		Early exit (n=5)		Total (n=92)	
	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C
Family Centered Care	100	53	100	80	100	84	100	64	100	54	100	29	100	20	100	60
Early Intervention	100	80	100	87	100	84	91	60	100	46	100	14	100	60	99	64
Special Education	93	21	100	60	100	53	91	30	100	31	93	0	100	20	97	34
Roles of Other Professionals	87	0	87	92	100	63	91	60	85	18	86	0	100	20	90	40
Comm. Skills and Team Part.	0	0	93	7	95	6	91	0	54	0	86	0	60	0	86	3
Interagency Coll.	0	0	73	0	90	47	91	10	31	0	0	0	0	0	46	18
Advocacy and Resp.	0	0	27	0	79	13	100	10	85	0	36	0	20	0	51	6

*includes 6 residents on individualized schedules
S: started module
C: completed module

Table 7: Pre and Post Tests Results: Paired t Tests

Module	**Type of test**	**Pre Test**	**Post test**	**Paired difference mean**	**t**	**df**	**2-tail significance**
Family Centered Care	*Knowledge based*	57.48 (12.37)	69.55 (12.48	12.07 (13.44)	4.84	29	0.00
	Comfort based	13.2 (4.83)	73.33 (11.98)	56.67 (11.18)	18.49	11	0.00
Early Intervention	*Knowledge based*	61.09 (9.92)	79.10 (8.95)	17.19 (10.73	8.32	26	0.00
	Comfort based	19.47 (7.62)	81.67 (13.98)	61.67 (12.83)	11.77	5	0.00
Special Education	*Knowledge based*	65.90 (12.94)	74.60 (9.14)	5.86 (10.93)	2.84	27	0.009
	Comfort based	28.00 (12.43)	76.00 (16.71)	56.17 (20.19)	6.81	5	0.001
Role of Other Professionals	*Knowledge based*	54.88 (17.32)	79.83 (13.10)	22.23 (14.55)	7.16	21	0.00
	Comfort based	28.00 (12.43)	100 -----	----	----	---	----
Communication Skills & Team Participation	*Knowledge based*	66.37 (16.17)	80.23 (13.87)	11.00 (13.76)	2.88	12	0.014
	Comfort based	31.29 (14.23)	----	----	----	---	----
Interagency Collaboration, etc.	*Knowledge Based*	67.21 (16.17)	85.73 (11.65)	18.36 (17.52)	3.38	10	0.006
	Comfort based	28.30 (9.80)	83.00 ----	----	----	---	----
Advocacy & Responsibility, etc.	*Knowledge based*	55.10 (19.21)	80.00 12.85	17.00 (21.44)	1.77	4	0.151
	Comfort based	39.00 (12.05)	71.00 (17.47)	28.80 (29.55)	2.18	4	0.095
Overall	*Knowledge based*	62.82 (12.81)	76.87 (12.09)	14.05 (14.20)	11.5	134	0.00
	Comfort based	13.67 (5.25)	73.3 (11.98)	59.67 (11.18)	18.49	11	0.00

TABLE 8A

KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHANGE
Jan 1997 - Jun 1997					
	1	2	*	42	*
	2	31	*	58	*
	3	23	*	79	*
		35	*	76	*
Jul 1997 - Dec 1997					
	1	1	56	81	25
		3	41	71	30
		4	56	48	-8
		5	59	75	16
		6	47	56	9
		7	50	74	24
		8	*	68	*
		9	41	59	18
		10	59	45	-14
		11	34	56	22
		12	66	61	-5
		13	*	53	*
		14	66	71	5
		15	53	52	-1
		16	31	65	34
		44	34	*	*
	2	2	39	68	29
		3	81	87	6
		4	55	71	16
		8	55	81	26
		9	71	*	*
		10	58	77	19
		11	58	71	13
		13	55	74	19
		15	58	74	16
		44	39	*	*
	3	44	18	*	*
	4	23	*	92	*
		28	52	*	*
		31	78	*	*
	5	37	74	*	*

TABLE 8A

KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHANGE
Jan 1998 - Jun 1998					
	2	1	68	84	16
		5	55	90	35
		6	58	*	*
		7	58	71	13
		12	65	84	19
		14	68	87	19
		16	55	81	26
	3	1	70	73	3
		2	70	76	6
		3	70	79	9
		4	61	91	30
		5	67	79	12
		7	70	67	-3
		8	67	82	15
		10	67	55	-12
		11	58	70	12
		12	61	79	18
		13	70	79	9
		14	70	79	9
		15	76	67	-9
		16	79	82	3
	4	10	63	67	4
		14	63	96	33
		17	67	*	*
		24	63	*	*
		25	67	*	*
	5	21	68	*	*
		27	81	*	*
	6	22	85	92	7
		23	83	*	*
		38	63	*	*
		39	54	*	*
	7	32	86	*	*
		34	75	*	*
		36	25	*	*
		39	77	*	*
		43	44	*	*
		44	19	*	*

TABLE 8A

KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHANGE
Jul 1998 - Dec 1998					
	1	68	61	55	-6
		69	58	81	23
		70	74	*	*
		71	71	74	3
		72	35	61	26
		73	81	90	9
		74	58	74	16
		75	61	81	20
		76	52	71	19
		77	65	68	3
		78	52	*	*
		79	65	77	12
		80	55	81	26
		81	71	61	-10
		82	74	71	-3
		83	65	94	29
		84	68	77	9
	2	68	61	94	33
		69	42	81	39
		70	68	87	19
		71	58	77	19
		73	71	81	10
		74	68	71	3
		75	58	*	*
		77	58	*	*
		78	52	*	*
		79	77	71	-6
		80	61	65	4
		82	77	87	10
		84	68	81	13
	3	71	79	82	3
		73	73	82	9
		74	61	76	15
		82	58	64	6
	4	1	71	92	21
		2	54	75	21
		3	83	96	13
		4	67	63	-4
		5	67	92	25
		11	71	67	-4
		13	71	88	17
		15	58	*	*
		16	67	92	25
	5	2	30	*	*
		7	59	86	27
		10	68	84	16
		11	70	92	22
		13	66	82	16
		16	65	*	*
	6	18	58	83	25
		24	67	*	*
		30	75	*	*
	7	18	78	63	-15
		23	80	*	*
		24	44	*	*
		29	56	*	*
		76	44	*	*

TABLE 8A

KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHANGE
Jan 1999 - Jun 1999					
	1	67	68	87	19
	2	67	68	81	13
		72	68	71	3
		83	65	97	32
	3	6	36	*	*
		9	76	55	-21
		67	70	82	12
		68	76	73	-3
		69	85	79	-6
		70	73	88	15
		72	73	79	6
		78	70	*	*
		79	56	64	8
		80	61	55	-6
		83	52	76	24
		84	70	70	0
	4	6	41	85	44
		7	67	83	16
		8	58	92	34
		12	75	79	4
		71	52	81	29
		74	22	52	30
		82	67	78	11
		84	41	70	29
	5	1	78	78	0
		4	78	92	14
		5	91	84	-7
		8	37	39	2
		14	86	68	-18
	6	2	48	*	*
		10	80	85	5
		11	53	100	47
		14	80	80	0
		31	90	*	*
		81	65	69	4
	7	10	71	93	22
		17	38	*	*
		22	38	*	*
		28	38	*	*
		30	56	81	25
		31	50	*	*
		81	69	*	*

TABLE 8A

KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHANGE
Jul 1999 - Dec 1999					
	4	67	44	96	52
		68	41	*	*
		69	19	*	*
		70	56	*	*
		72	22	*	*
		78	33	*	*
		79	26	59	33
		80	48	67	19
		83	37	74	37
	5	71	55	86	31
		74	43	*	*
		82	60	79	19
		83	74	86	12
		84	78	87	9
	6	1	73	*	*
		3	47	*	*
		4	67	100	33
		5	73	*	*
		7	40	80	40
		8	73	67	-6
		12	53	*	*
		13	80	100	20
		16	73	*	*
		26	60	87	27
		83	73	*	*
	7	4	64	74	10
		14	50	93	43

TABLE 8A

COMFORT BASED
PRE/POST TEST SCORES

TIMEBLK	MODULE#	ID	% PRE	% POST	% CHANGE
Jul 1999 - Dec 1999					
	1	85	10	68	58
		86	14	76	62
		87	14	*	*
		88	10	70	60
		89	10	76	66
		90	10	68	58
		91	26	68	42
		92	10	*	*
		93	14	88	74
		94	14	88	74
		95	14	82	68
		96	10	54	44
		97	10	*	*
		98	22	88	66
		99	10	54	44
	2	85	18	*	*
		86	23	89	66
		87	24	*	*
		88	15	100	85
		89	13	*	*
		91	18	*	*
		92	28	*	*
		93	15	*	*
		94	18	*	*
		95	10	*	*
		96	13	70	57
		98	38	93	55
	3	85	14	*	*
		86	16	91	75
		89	14	*	*
		91	16	*	*
		93	13	*	*
	4	9	50	*	*
		73	23	100	77
	5	69	53	*	*
	7	7	54	62	8
		8	46	76	30

TABLE 8A

COMFORT BASED
PRE/POST TEST SCORES

TIMEBLK	MODULE#	ID	% PRE	% POST	% CHANGE
Jan 2000 - Jun 2000					
	2	90	20	68	48
		97	28	*	*
		99	11	70	59
	3	75	19	*	*
		77	16	*	*
		87	33	*	*
		88	11	96	85
		90	14	69	55
		94	11	*	*
		95	10	*	*
		96	16	64	48
		98	51	83	32
		99	11	53	42
	4	85	13	*	*
		86	37	*	*
		87	23	*	*
		88	23	*	*
		89	27	*	*
		90	23	*	*
		91	15	*	*
		93	48	*	*
		94	27	*	*
		95	15	*	*
		96	23	*	*
		98	50	*	*
		99	23	*	*
	5	68	30	*	*
		70	23	*	*
		73	10	*	*
		78	40	*	*
		79	40	*	*
		80	23	*	*
	6	6	43	*	*
		67	33	*	*
		68	37	*	*
		69	35	*	*
		70	37	*	*
		71	15	*	*
		73	17	*	*
		79	23	83	60
		82	23	*	*
		84	20	*	*
	7	1	34	76	42
		11	46	*	*
		12	46	76	30
		13	18	94	76
		16	42	42	0
		84	26	*	*

*end of program - post not expected

TABLE 8B

MED/PEDS
KNOWLEDGE BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHG
Jul 1997 - Dec 1997					
	1	6	47	56	9
		9	41	59	18
	2	9	71		
Jan 1998 - Jun 1998					
	3	6	58		
Jul 1998 - Dec 1998					
	1	75	61	81	20
		77	65	68	3
	2	75	58		
		77	58		
Jan 1999 - Jun 1999					
	3	6	36		
		9	55	56	1
	4	6	41	85	44

TABLE 8B

MED/PEDS
COMFORT BASED
PRE/POST TEST SCORES

TIMEBLOCK	MODULE#	ID	% PRE	% POST	% CHG
Jul 1999 - Dec 1999					
	1	92	10		
		97	10		
	2	92	28	*	
	4	9	50	*	
		26	60	87	27
Jan 2000 - Jun 2000					
	2	97	28	*	
	3	75	19	*	
		77	16	*	
	6	6	43	*	

***end of program - post not expected**

Table 9A

Self Evaluation - Physician Level 1

Module	Mean Agreement Score												Percent of Residents Agreeing			
	Opportunity to Observe Practices				Increased Knowledge of Practices				Satisfaction in Components				Visit Beneficial			
(component #) —>	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care	87 (38)	85 (19)	88 (34)	*	98 (38)	94 (20)	92 (35)	*	96 (35)	94 (20)	97 (35)	*	94 (34)	94 (18)	97 (35)	*
Early Intervention	90 (26)	86 (24)	*	*	99 (27)	90 (25)	*	*	95 (27)	92 (25)	*	*	100 (27)	90 (20)	*	*
Special Education	88 (39)	84 (6)	93 (22)	*	87 (39)	95 (6)	93 (21)	*	88 (39)	96 (6)	99 (21)	*	95 (38)	100 (6)	100 (21)	*
Team Based Service Models: The Role of Other Professionals	100 (1)	100 (2)	99 (4)	*	100 (1)	100 (2)	94 (4)	*	100 (1)	100 (2)	92 (4)	*	100 (1)	100 (2)	100 (4)	*
Communication Skills and Team Participation																
Interagency Collaboration , Service Integration, and Resource Allocation																*
Advocacy and Responsibility and the Legislative Process			97 (3)				97 (3)				100 (3)				100 (2)	

* component number not applicable to this module

Table 9B

Self Evaluation - Physician Level 2

	Mean Agreement Score												Percent of Residents Agreeing			
Module	Opportunity to Observe Practices				Increased Knowledge of Practices				Satisfaction in Components				Visit Beneficial			
(component # —>)	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care	94 (4)	82 (11)	93 (9)	*	100 (4)	93 (11)	98 (9)	*	88 (4)	100 (11)	87 (9)	*	100 (4)	100 (10)	100 (7)	*
Early Intervention	84 (11)	96 (8)	*	*	99 (11)	98 (8)	*	*	91 (11)	98 (8)	*	*	100 (10)	100 (8)	*	*
Special Education	79 (29)	80 (10)	91 (11)	*	89 (29)	89 (10)	87 (11)	*	89 (29)	98 (10)	87 (11)	*	93 (29)	100 (9)	91 (11)	*
Team Based Service Models: The Role of Other Professionals	90 (26)	91 (32)	92 (29)	*	86 (26)	91 (32)	97 (29)	*	92 (25)	97 (32)	96 (29)	*	92 (25)	97 (30)	100 (26)	*
Communication Skills Team Participation	93 (13)	96 (22)	82 (7)	96 (5)	95 (15)	93 (22)	100 (6)	100 (4)	96 (14)	95 (21)	98 (7)	97 (5)	100 (12)	95 (20)	100 (5)	100 (4)
Interagency Collaboration, Service Integration, and Resource Allocation	93 (2)	100 (1)		*	97 (4)	100 (1)		*	100 (4)	100 (1)		*	100 (4)	100 (1)		*
Advocacy and Responsibility and the Legislative Process	89 (3)		96 (5)		90 (3)		98 (5)		83 (3)		90 (5)		100 (3)		100 (5)	

* component number is not applicable to this module

Table 9C

Self Evaluation - Physician Level 3

	Mean Agreement Score												Percent of Residents Agreeing			
Module	Opportunity to Observe Practices				Increased Knowledge of Practices				Satisfaction in Components				Visit Beneficial			
(component # →)	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care	100 (3)	70 (3)	96 (7)	*	100 (3)	98 (3)	96 (7)	*	100 (3)	100 (3)	97 (7)	*	100 (3)	100 (3)	100 (7)	*
Early Intervention	87 (3)	100 (2)	*	*	100 (3)	96 (2)	*	*	100 (3)	88 (2)	*	*	100 (3)	100 (2)	*	*
Special Education	88 (10)	94 (5)	82 (3)	*	96 (10)	98 (5)	100 (3)	*	95 (10)	95 (5)	100 (3)	*	100 (10)	100 (4)	100 (2)	*
Team Based Service Models: The Role of Other Professionals	96 (12)	87 (9)	85 (4)	*	90 (12)	95 (9)	98 (4)	*	87 (12)	100 (9)	94 (4)	*	90 (11)	100 (9)	100 (3)	*
Communication Skills and Team Participation		94 (16)				97 (15)				90 (16)				93 (14)		
Interagency Collaboration, Service Integration, and Resource Allocation	94 (13)	92 (10)		*	96 (14)	96 (12)		*	98 (14)	98 (12)		*	100 (14)	100 (12)		*
Advocacy and Responsibility and the Legislative Process	95 (16)	95 (4)	84 (13)	100 (7)	98 (16)	96 (6)	88 (13)	99 (11)	94 (16)	92 (6)	85 (12)	100 (3)	94 (16)	100 (6)	86 (14)	100 (11)

* component number is not applicable to this module

Table 9D

Self Evaluation - Physician Level 4

	Mean Agreement Score												Percent of Residents Agreeing			
Module	Opportunity to Observe Practices				Increased Knowledge of Practices				Satisfaction in Components				Visit Beneficial			
(component # →)	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care				*				*				*				*
Early Intervention			*	*			*	*			*	*			*	*
Special Education				*				*				*				*
Team Based Service Models: The Role of Other Professionals				*				*				*				*
Communication Skills and Team Participation		91 (1)				100 (1)				100 (1)				100 (1)		
Interagency Collaboration, Service Integration, and Resource Allocation		100 (1)		*		100 (1)		*		100 (1)		*		100 (1)		*
Advocacy and Responsibility and the Legislative Process				100 (2)				100 (2)				100 (2)				100 (2)

* component number is not applicable to this module

Table 10

Self Evaluation – ALL Physician Levels Combined

	Mean Agreement Score												Percent of Residents Agreeing			
Module	Opportunity to Observe Practices				Increased Knowledge of Practices				Satisfaction in Components				Visit Beneficial			
(component #) —>	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care	89 (45)	82 (33)	90 (50)	*	98 (45)	94 (34)	94 (51)	*	96 (42)	96 (34)	95 (51)	*	95 (41)	97 (31)	98 (49)	*
Early Intervention	88 (40)	89 (34)	*	*	99 (41)	92 (35)	*	*	95 (41)	93 (35)	*	*	100 (40)	93 (30)	*	*
Special Education	85 (78)	85 (21)	92 (36)	*	89 (78)	93 (21)	92 (35)	*	89 (78)	96 (21)	95 (35)	*	95 (77)	100 (19)	97 (34)	*
Team Based Service Models: The Role of Other Professionals	92 (39)	91 (43)	92 (37)	*	88 (39)	92 (43)	97 (37)	*	91 (38)	98 (43)	95 (37)	*	92 (37)	98 (41)	100 (33)	*
Communication Skills and Team Participation	93 (13)	95 (39)	82 (7)	96 (5)	95 (15)	95 (80)	100 (6)	100 (4)	96 (14)	93 (38)	98 (7)	97 (5)	100 (12)	94 (35)	100 (5)	100 (4)
Interagency Collaboration , Service Integration, and Resource Allocation	93 (15)	93 (12)			97 (18)	96 (14)			98 (18)	98 (14)			100 (18)	100 (14)		*
Advocacy and Responsibility and the Legislative Process	94 (19)	95 (4)	88 (21)	100 (9)	97 (19)	96 (6)	92 (21)	99 (13)	92 (19)	92 (6)	89 (20)	100 (13)	95 (19)	100 (6)	90 (21)	100 (13)

* component number not applicable to this module

Table 11

Preceptor Evaluation Forms – All Physician Levels Combined

	Mean Agreement Score												Percent of Preceptors Agreeing							
Module	Resident Used Didactic Information				Residents' General Performance				Beneficial Experience for Preceptor				Resident Demonstrated Appropriate Professional Behavior				Satisfied with Quality of Resident			
(component # —>)	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5	2	3	4	5
Family Centered Care	100 (31)	93 (9)	77 (38)	*	100 (31)	99 (9)	95 (38)	*	100 (29)	83 (9)	92 (36)	*	100 (30)	100 (3)	100 (37)	*	100 (30)	100 (3)	100 (36)	*
Early Intervention	91 (34)	90 (28)		*	97 (38)	98 (17)		*	94 (38)	85 (13)		*	96 (26)	100 (17)		*	96 (27)	100 (12)		*
Special Education	95 (58)	100 (2)	63 (22)		99 (59)	100 (2)	91 (23)		96 (58)	100 (2)	84 (22)		100 (40)	100 (2)	96 (23)		100 (58)	100 (2)	100 (23)	
Team Based Service Models: The Role of Other Professionals	94 (23)	97 (36)	67 (25)	*	99 (22)	98 (37)	97 (27)	*	93 (20)	97 (30)	83 (23)	*	100 (19)	100 (27)	96 (26)	*	100 (20)	100 (31)	96 (25)	*
Communication Skills and Team Participation	97 (10)	95 (28)	94 (5)	100 (1)	100 (10)	97 (28)	100 (6)	100 (1)	100 (10)	90 (27)	83 (6)	100 (1)	100 (10)	100 (28)	100 (5)	100 (1)	100 (10)	100 (28)	100 (5)	100 (1)
Interagency Collaboration, Service Integration, and Resource Allocation	100 (9)	100 (8)	82 (1)	*	100 (9)	97 (9)	100 (1)	*	100 (9)	98 (9)	50 (1)	*	100 (8)	100 (9)	100 (1)	*	100 (9)	100 (9)	100 (1)	*
Advocacy and Responsibility and the Legislative Process	100 (15)	95 (4)	84 (20)	100 (4)	98 15)	100 (5)	97 (22)	100 (4)	72 (15)	87 (5)	85 (22)	92 (4)	100 (15)	100 (5)	95 (22)	100 (4)	100 (15)	100 (5)	95 (22)	100 (4)

* component number not applicable to this module

Table 12

Preceptor Evaluation Forms—Parents and Educators

All Physician Levels Combined

Preceptor	**Resident Used Didactic Information**	**Resident's General Performance**	**Beneficial Experience for Preceptor**	**Resident Demonstrated Appropriate Professional Behavior**	**Satisfied with Quality of Resident**
Parent	99% (59)	100% (59)	97% (57)	100% (52)	100% (52)
Educator	94% (160)	97% (163)	93% (158)	98% (124)	99% (137)

Table 13

Preceptor Form B Qualitative Information

Question Number	Themes
Question 1: Please describe the benefits of your visit with the pediatric resident.	1-communication 2-helpful instruction from resident 99-no response
Question 2: What will you do as a result of this visit?	1-increase involvement with various professionals 2-increase resources for child and/or family 3-increase relation between family and physician 4-increased awareness of child's need 99-no response
Question 3: What do you expect the resident to do as a result of this visit?	1-collaborate with other professionals 2-increase assistance to child and/or family 3-increase awareness of issues faced 99-no response
Question 4: Do you have any additional concerns that need to be addressed?	1-increased collaboration between professionals 2-overall satisfaction with resident and/or visit 3-Preceptor follow-up 99-no response

Table 13 (continued)

ID	**Module**	**Question**	**Theme**	**Response**	**Over-all Comm-ents**
34	Special Education	1	1	Excellent feedback	+
		1	2	Her feedback on good ways to deal with this family was very helpful	+
		2	1	Speak to more health professionals concerning child; collaborate with other professionals	+
		2	2	Seek alternative placement situations to assist his family as well as provide appropriate social interaction situations for him.	+
		3	1	Collaborate with other professionals	+
		3	2	Seek assistance for mom at home	+
		4	99		
18	Special Education/ extra visit	1	1	Much better communication; I hope the lines of communication continue	+
		2	3	I will feel more confident that the school's needs are understood and I've made a real connection with the clinic; we all need to work together	+
		3	3	Be more aware of the inadequacy of some parents' reporting and their follow through. Realize the value of a school visit	+
		4	1	I hope the line of communication continues. We all need to work together.	+

Table 13 (continued)

ID	Module	Question	Theme	Response	Over-all Comm-ents
12	Special Education	1	2	The resident would be able to answer any questions I had for her.	+
		2	4	I will pay closer attention to child's physical needs and how they affect her in the classroom.	+
		3	2	And can now adapt anything she does outside of the classroom to better suit the student's needs.	+
		4	99		
14	Special Education	1	1	To explain the goals that we have been working on and share ideas with the resident.	+
		2	2	Continue to teach and support the family and child in ways to promote his overall development	+
		3	1	Ask for more information from the parents, and be willing to contact Birth to Three providers for input or to address concerns.	+
		4	2	She was a good listener, asked questions appropriately to the situation.	+
13	Team Participation	1	2	She was able to supply information that was created at the IFSP.	+
		2	2	Continue service uninterrupted, get doctor appointment sooner, get Audiology exam every 6 months.	+
		3	1	Be a resource to me	+
		3	2	Continue on helping the family	+
		4	2	She is wonderful and supportive-can you turn out more doctors like her?	+
12	Special Education	1	2	Teachers and doctors were able to dialogue regarding student medical needs	+
		2	1	Look forward to other visitors	+

Table 13 (continued)

ID	Module	Question	Theme	Response	Over-all Comm-ents
		3	3	Become more aware of how a school operates, and of the academic demands placed on identified students	+
		4	99		
77	Family Centered Care	1	2	Resident gave us the opportunity to know the type of needs and concerns we have in the home.	+
		2	3	I will ask to be visited again, in case I have other concerns.	+
		3	3	Have in mind whatever needs we may have.	+
		4	99		
13	Team Participation and facilitation	1	2	Doctor was able to taken on some issues that I have not been able to get resources for.	+
		2	3	I will feel confident that the UConn Health Center will contact the parents to set up the needed appointment	+
		3	2	Continue her excellent care and constant monitoring of this very needy child.	+
		4	3	I would like to know what was accomplished at UConn Health Center.	+
13	Team Participation and facilitation	1	1	Considered placements were discussed, needs to be addressed by school system.	+
		2	4	Feel confident that at the PPT, this child will receive the needed services at the urging of the Doctor.	+
		3	2	Be strong and demanding that child gets all that he needs	+
		4	2	I would hope that more doctors of her caliber are being sought. She is absolutely fantastic.	+
1	Special Education	1	1	It created a nice link in the total care system.	+

Table 13 (continued)

ID	Module	Question	Theme	Response	Over-all Comm-ents
		2	1	Maybe invite other physicians to be that kind of a team member.	+
		3	1	Talk among his colleagues how important it is to keep in touch with the Birth to three providers.	+
		4	99		

Project Impact

This project has had a profound impact on how a pediatrician approaches the family who has a child with a disability. Prior to this project, no pediatric residency program in the country offered a longitudinal experience on children with disabilities and few programs required any training for their residents. Some programs, including the University of Connecticut where this project was conducted, offered 2-4 week block electives on children with disabilities, but these electives were generally chosen by a few residents who were already motivated to learn about these children and their families. Additionally, these electives generally approached the subject from the medical model, and not from the family's psychosocial perspective. This project changed all of that. The residents who participated in this first in the nation longitudinal, required, in-depth rotation on children with disabilities are now more familiar with family centered care, and are interacting with early interventionists and school programs on a regular basis.

Post Residency Survey

How do we know this? A partial answer comes from a survey conducted in the summer of 2000. Twelve of the twenty-six residents who graduated in the previous 2 years of the project (1998 and 1999) agreed to be interviewed over the telephone. They were asked a series of questions on their use of curriculum material since beginning practice one to two years previously. A copy of the survey questions can be found in appendix V. Among the interesting data are:

> 100% of those surveyed had referred patients and families to Early Intervention.
>
> 92% of those surveyed had referred patients and families to Special Education Services.

75% of those surveyed had reviewed an IFSP.

83% of those surveyed had reviewed an IEP.

83% of those surveyed had interacted with an EI provider, and/or with a school system.

75% of those surveyed had made referrals to agencies to help families procure additional funding.

Open-ended questions in this survey were scrutinized for connecting statements/phrases that could be woven into overall themes. These themes are also available in appendix V. Among the themes are:

> **Knowing the system** made implementing family centered care easier.
>
> **Community visits** (within the curriculum) and **familiarity with the system** made it easier to serve families needing Early Intervention services and Special Education services.
> Knowing the background of physical therapists, occupational therapists and other professionals made it easier to **help families** to know what to expect. It also allowed physicians to deliver **better patient care** because the physician had a better understanding of the therapist's work. It also led to **earlier referrals**, because the physician was comfortable seeking this type of intervention.

Comments from the physician's interviewed, about the curriculum itself, were overwhelmingly positive. They included:

> "I really feel at an advantage because of what I've learned."
>
> "The biggest advantage was having information not covered elsewhere."
>
> "It opened my eyes to mainstream family-centered ways of dealing with kids with disabilities—compared to the segregation I grew up with."

Graduating Resident Interview

In addition to the above survey, impact on the current resident physicians was measured by conducting a personal interview with every graduating resident of the class of 2000. There were 13 of these residents, and all had progressed through the entire 3 years of the curriculum. This survey consisted of all open-ended questions, and, again, the answers were scrutinized for statements/phrases that could be woven into overall themes. Among other things, we asked each resident to tell us how they had made use of the material as they progressed through each year of the curriculum. Following are examples of their answers.

First year curriculum--examples of how the residents had already used the knowledge garnered:

> Informing parents about what to expect from the evaluation, the process, and the development of an IFSP.
>
> Feeling comfortable referring to EI and to Special Education.
>
> Improved ability to identify families who could benefit from services.
>
> Informed parents about their right to request an IEP, and what to expect during the process.
>
> Called a child's social worker to advocate for that child to be moved to a school closer to home.

Second year curriculum—example of how the residents had already used the knowledge garnered:

> Advised families on what to expect in a specialty clinic visit.
>
> Improved communication with other professionals--phone calls and letters sent to schools when resident unable to be present at IEP.
>
> Taking extra time with families to answer questions because

of "knowing the feeling of how overwhelming it is and being sensitive to that."

Third year of the curriculum—examples of how the residents had used the knowledge garnered:

> Wrote letters to various agencies to help families obtain additional funding.
>
> Wrote letters and made phone calls to politicians about issues important in the lives of children with disabilities.
>
> Researched and designed an information brochure on EI services in another state.

Overall impression of the curriculum--items that were memorable in the resident's opinion:

> Community visits with EI & Special Education.
>
> Legislative Office Building visits and learning about the legislative system.
>
> Advocacy projects.

There were a few things that the residents did not like about the 3 year curriculum, including the paper work and redundant visits; however, they all recognized that as far as possible, changes had been made over the years addressing almost all of their concerns as they had arisen. A copy of the survey and derived themes can be found in appendix T.

Advocacy Projects

A third way we can measure the impact of this project on new physicians is by looking at the 15 advocacy projects completed. Two of these were done as electives, prior to our mandating it as part of the curriculum. One of the elective projects involved the resident surveying every pediatric residency programs in the country and compiling data on advocacy training. This was then presented at an American Academy of Pediatrics annual chapter meeting, thus disseminating the idea of the importance of advocacy to a large number of Connecticut pediatricians. The Children with Disabilities rotation was recognized as having been instrumental to the idea of the survey.

Another resident researched the impact of horseback riding on children with disabilities. She is now investigating the possibility of opening a therapeutic riding school on her farm, even as she continues her training in fellowship.

Two residents, who will be dual board certified in Medicine and Pediatrics, helped to develop a full day symposium on the transitioning of adolescents with disabilities into the adult health care system. These residents commented on how advocating for adolescents with disabilities had given them a mission for their careers involving patients all across the lifespan.

Another resident, who was moving to practice in New Jersey, was invited by the Early Intervention Administrator of that state to contact her on his arrival, so that he could become involved for action at the systems level. This occurred as a direct result of the resident researching available services in the state, as part of his advocacy project. The conversation evolved into a discussion of the resident's training as a result of this program, and led to the invitation.

There are similar stories woven throughout all the advocacy projects, but the above serve well to illustrate the influence of the curriculum on physicians in training, and therefore on children with disabilities and their families. A full list of the 15 advocacy projects can be found in appendix K.

Ninety-two physicians in training were impacted at least partially by this curriculum. As these physicians graduate and disseminate across the country, the full effect of their training will be felt by families not only in Connecticut, but throughout the North East, and as far away as California (where at least one graduate has set-up practice). As most physicians have anywhere from 2000 to 5000 patients in their practice, and as the population of children with disabilities grows, the influence of this project on patients, families, and systems, will be profound. Since most physicians are part of a group practice, we can assume that partners in these practices will be influenced by the physicians who have experienced this curriculum. It seems fair, therefore, to speculate that this will also prove to be a means by which the information from the project will be disseminated.

National Recognition

The Project Director and Co-Director presented workshops at the annual meeting of The Association of Pediatric Program Directors for 2 consecutive years. The meetings took place in New Orleans and San Francisco, respectively. The title of the workshops were:

> "Teaching Pediatric Residents to Care for Children with Disabilities: Putting it into Action."
>
> "The Recruitment Process: A Panel."
>
> "Curriculum to Teach Residents to Care for Children with Disabilities III: Evidence of Effectiveness."

The workshops were met with enthusiasm and requests for copies of the curriculum. The main concerns of the audiences were the difficulties encountered in scheduling a longitudinal experience in an already packed 3 year residency curriculum, and the difficulty of funding such a project. Copies of the curriculum were sent to those who had requested it. As a result of the feedback from these workshops, letters were mailed to a number of Residency Program Directors around the country in the fall of 1999, inquiring about their interest in implementing a similar curriculum in their program, should funding be found. Sixteen Residency Program Directors wrote letters of support for this proposal, but as of spring 2000, no funding has been secured. Nevertheless, this Project Director is continuing to pursue all possible avenues of support to disseminate the curriculum around the country.

Additional recognition for the project came from the newspaper, the Hartford Courant. In an article entitled "Linking up for Students" by Warren Woodbury, Jr., the collaboration between the Rocky Hill School System and the UCONN Pediatric Residency Program, through the Children with Disabilities Rotation, was lauded. A copy of the article can be found in appendix U.

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APPENDIX A

Project Staff Vitae

Eileen R. Fisk, M.D.
Assistant Professor of Pediatrics

Office Address:

University of Connecticut
Department of Pediatrics,
Division of Child and Family Studies
263 Farmington Avenue
Farmington CT 06032
(860) 679-1500
(860) 241-5428 (pager)
fisk@up.uchc.edu (Email)

Home Address:

68 Whitman Avenue
West Hartford, CT 06107
(860) 313-1394

Academic Appointments:

Assistant Professor of Pediatrics,
University of Connecticut. 1999-present

Education

Residency:

University of Connecticut Program in Pediatrics
Connecticut Children's Medical Center
Resident in Pediatrics, 1996-1999.
Residency Director: Edwin L. Zalneraitis, M.D.
Physician-in-Chief: Paul Dworkin, M.D., 1998-present.
John Raye, M.D., 1996-1998.

Medical:

Boston University School of Medicine
M.D., 1996
Boston, Massachusetts

Undergraduate:

Tufts University
B.S. Biopsychology, 1992
Medford, Massachusetts

Board Certification:

United States Medical Licensing Examination
Diplomate, 1997

American Board of Pediatrics
Diplomate, 1999

Licensure

State of Connecticut # 037673
April, 1999

Professional Societies:

American Academy of Pediatrics
1996-present

Massachusetts Medical Society
1996-2000.
Medical student member, 1992-1996

Professional Activities:

American Academy of Pediatrics Key Contact
for legislative issues, 1998-present

Executive Committee, Connecticut
Chapter of the American Academy of Pediatrics,
1999-present

Legislative Committee, Connecticut
Chapter of the American Academy of Pediatrics,
1999-present

Planning Committee for Symposium on the Transitional
Care of Adolescents with Chronic Disease/Disability,
Connecticut Children's Medical Center
1999-2000

Awards:

University of Connecticut Program in Pediatrics
Chair's Award, 1999

Boston University Stephen R. Preblud, M.D., Memorial
Award In Pediatrics, 1996

Boston University Center for Primary Care Award
For Excellence in Generalist Medicine, 1996

Psi Chi, National Honor Society
For Psychology, 1992

Community Service:

Founder and Organizer, First Annual Raye Day,
held in honor of John Raye, M.D.,
Physician-in-Chief, Connecticut Children's
Medical Center, on the occasion of his retirement.
An annual day of fun and festivity for the children of the
city of Hartford. 1998

Reading Program organizer for Connecticut Children's Medical Center Primary Care Center. 1998

Co-Chair, Primary Care Society, Boston University School of Medicine. 1993-1994

Volunteer, Eileen Tully Home for mentally retarded women. Lynn, Massachusetts, 1991-1993

Organizer of volunteer scribes for visually impaired students at North Shore Community College Beverly, Massachusetts 1989.

Experience

University of Connecticut:	Attending Physician in Pediatrics, Burgdorf/Fleet Health Center, Hartford, CT. 1999-present Medical Consultant, Division of Child and Family Studies, 1999-present
North Shore Community College:	Member of the Board of Trustees. Danvers, Massachusetts. 1995-1999
Lynn Community Health Center:	Summer externship, 1993. Organized tracking system for the community's children-at-risk. Lynn, Massachusetts.
North Shore Association for Retarded Citizens:	Respite care for mentally retarded children and adults. 1990-1991. Salem, Massachusetts.
Trans World Airlines:	Training Program Designer, Training Instructor, Supervisor of Flight Service Managers and Pursers, Domestic and International Flight Attendant. 1969-1988. Extensive exposure to multi-cultural environments through work and travel.
Residency Research:	A Survey of Advocacy Training in United States Pediatric Residency Programs.

Presentations:

Fisk, ER. Abuse in Children with Disabilities: Is There an Increased Risk? Grand Rounds. Saint Francis Hospital & Medical Center. Hartford, CT. 2000

Fisk, ER. Strengthening Families through Home Visitation. Charlotte Hungerford Hospital, Torrington, CT. 2000

Fisk, ER. A Survey of Advocacy Training in U.S. Pediatric Residency Programs. Connecticut Chapter of the American Academy of Pediatrics' annual meeting. Westbrook, CT. 1999

Fisk, ER. Primary Care for the Child with Down's Syndrome, from the Generalist's Perspective. Case Management, Connecticut Children's Medical Center, Hartford, CT. 1999.

Fisk, ER. Injury Prevention and the Use of Child Restraint Systems in Automobiles and Commercial Aircraft. Case Management, Connecticut Children's Medical Center, Hartford, CT. 1998

Fisk, ER. Adolescents and Acne: The Physical and Psychological Effects. St. Francis Hospital Medical Center, Hartford, CT. 1998

Fisk, ER. Adolescent Parenthood: The Effects on the Adolescent and the Child from a Developmental Perspective. St. Francis Hospital Medical Center, Hartford, CT. 1997

Fisk, ER. The Art of Lobbying: The Legislative System and Advocacy for Pediatric Patients. Continuity Practice Presentation, Connecticut Children's Medical Center. 1997

Fisk, ER. The Pathophysiology, Clinical Presentation, and Treatment, of Dermatomyositis. Case Management, Connecticut Children's Medical Center,. 1997

APPENDIX B

Bibliography

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Woodruff, G., McGonigel, M., Garland, C., Zeitlin, S., Chazkel-Hochman, J., Shanahan, K., Toole, A., & Vincent, L. (1985). Planning programs for infants. Chapel Hill, NC: University of North Carolina.

APPENDIX C

Past Experience Form

Children with Disabilities Rotation

Previous Experience

Name:________________________________PL:____________________Date:_________

This questionnaire is designed to determine the previous experience each resident has had in disabilities prior to his/her entry into the CCMC Pediatric or Med/Peds Residency Program. Using this information as a baseline, we can then track your progress as you begin to implement the curriculum through the three years of this longitudinal rotation.

Year 1

Have you had any formal training in human growth and development, disabilities, etc. in college or medical school? If yes, please list these experiences.

Have you had any volunteer experience in group homes, hospitals etc. in dealing with an individual with a disability? If yes, please briefly explain these experiences.

Do you have any personal experience with an individual with a disability - e.g., friend, family member? If yes, please explain briefly.

Have you referred any patient to Birth to Three and/or special education?

If yes, how many referrals have you made to Birth to Three and how many referrals to special education? Birth to Three ____________________ Special Education __________________

If no, do you know how to refer to Birth to Three?

If no, do you know how to refer to special education?

Year 2

Have you had any exposure to non-medical professionals involved in the care of children with disabilities - e.g., speech/language pathologists, audiologists, physical or occupational therapists or teachers? If yes, what professionals and in what capacity?

Have you had any experience observing or working with teams? If so, what kind? What was your role on the team?

Year 3

Have you had any experience with legislative initiatives, contacted a legislator, etc.? If yes, please explain briefly.

Have you collaborated with any agencies on behalf of a patient? If yes, please explain briefly.

APPENDIX D

Medical Consultant's Job Description-Year 3

University of Connecticut Health Center
School of Medicine

March 23, 1999

Paul Dworkin, M.D.
Professor and Chair
Department of Pediatrics
Physician-in-Chief
Connecticut Children's Medical Center
120 Washington Street
Hartford, CT 06151

Dear Paul:

I am pleased to be able to offer Eileen Fiske, M.D., a half-time position in the Division of Child and Family Studies. Her position will be funded by a Personnel Preparation Grant from the Office of Special Education Programs, U.S. Department of Education (#H029G60103) from July 1, 1999 - June 30, 2000. Her specific job duties will include:

1) orienting and serving as liaison for chief residents, continuity clinic preceptors and specialty clinic preceptors on curriculum requirements for residents
2) participating in orientation for early intervention and special education teachers, school administrators and families who serve as community and home visiting sites for residents
3) meeting with each resident a minimum of twice yearly for the purpose of:
    a) discussing curriculum applications to patients;
    b) providing feedback on residents' performance in curriculum experiences; and
    c) gathering information from the residents on the residents' acquisition of curriculum content.
4) observing and providing feedback to residents during curriculum experiences and continuity clinics

qual Opportunity Employer

Farmington Avenue
igton, Connecticut 06030

5) refining the residents' curriculum as necessary

6) refining the curriculum evaluation plan as necessary

7) participate in planning residents' seminars

8) writing up residents' evaluation for federal reporting purposes

9) attending monthly division staff meetings

If you need any additional information, please let me know.

Sincerely,

Mary Beth Bruder, Ph.D.
Professor and Director
Division of Child and Family Studies

APPENDIX E

Additions to Curriculum:
Articles From the American Academy of Pediatrics
Hospital for Special Care Forms and Addendum Articles
Adaptive Equipment Specialty Clinic Forms and Addendum Material
NICU Follow-Up Specialty Clinic Addendum Articles

December 10, 1997

Donna Hoffman
American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, Illinois 60007-1098

Dear Ms. Hoffman,

I am writing to request permission to copy 6 articles from the journal Pediatrics. The articles include:

> The Role of the Pediatrician in Implementing the Americans With disabilities Act: Subject Review, Pediatrics, Vol. 98 No. 1 July 1996
>
> The Role of the Pediatrician in Prescribing Therapy Services for Children With Motor Disabilities, Pediatrics, Vol. 98 No. 2 August 1996
>
> Why Supplemental Security Income Is Important for Children and Adolescents, Pediatrics, Vol. 95 No. 4 April 1995
>
> Screening Infants and Young Children for Developmental Disabilities, Pediatrics, Vol. 93 No. 5 May 1994
>
> Provision of Related Services for Children With Chronic Disabilities, Pediatrics, Vol. 92 No. 6 December 1993
>
> Pediatrician's Role in the Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP), Pediatrics, Vol. 89 No. 2 February 1992

These articles would be included as appendices in a curriculum developed for pediatric residents rotating through the, "Children With Disabilities Rotation" at The University of Connecticut. This curriculum is used strictly for educational purposes and is distributed free of charge. There will be approximately 25 copies distributed each year for the next 3 years.

Please feel free to call me at (860) 679-4632 or fax any information back to (860) 679-1368 at my attention. Thank you for your considerations.

Sincerely,

Mary Beth Bruder Ph.D.
Professor and Director
Child and Family Studies

AMERICAN ACADEMY OF PEDIATRICS

Screening Infants and Young Children for Developmental Disabilities

Committee on Children With Disabilities (P.E9414)

Early identification of children with developmental disabilities leads to effective therapy of conditions for which definitive treatment is available. However, even in those instances in which the condition cannot be fully reversed, early intervention improves children's outcomes and enables families to develop the strategies and obtain the resources for successful family functioning. Much of the impact of early intervention results from fostering a more comfortable and developmentally appropriate interaction between the parents and their child with a disability.

DEFINITION

Screening is a "brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment."[1] Early childhood developmental screening does not consist of administering a single instrument at one point in time, but rather is a set of processes and procedures used over time. The following guidelines are recommended by the Task Force on Screening and Assessment of the National Early Childhood Technical Assistance System[1]:

- Screening should be viewed as a service and part of the intervention process.
- Screening processes, procedures, and instruments should only be used for their intended purpose.
- Multiple sources of information should be utilized.
- Screening should be performed on a recurrent or periodic basis.
- Screening should be viewed as only one path to further assessment and the acquisition of services, with social and medical risk factors also being considered in decisions about evaluation and intervention.
- Procedures should be reliable and valid.
- Family members should be included as part of the process.
- Screening is more effective when familiar tasks and settings are used.
- Procedures must be culturally sensitive.
- Screening should be performed by individuals with training in the procedures.

Screening does not measure a child's intelligence quotient, rather it is aimed at identifying those children who may need more comprehensive evaluations. Such evaluations may lead to the development of an interdisciplinary comprehensive plan of remediation for a child with a disability, to a realization that there is no significant problem, or to a decision that further observation is warranted.[1] The act of screening also serves the purpose of clearly communicating to parents the pediatrician's interest in the development as well as the physical health of the child.[2] If appropriate, the pediatrician should foster awareness and acceptance of the possible developmental disability.

Public Law 99-457 (reauthorized as Pub L 102-119, The Individuals with Disabilities Education Act)[3] mandates early identification of, and intervention for, developmental disabilities. Since the passage of that law, the emphasis in screening has shifted to a younger age, with the current focus being on infants and children birth through 2 years of age.[3] This is an age at which the pediatrician is very closely involved with children and families and is in a position to have significant impact on the course of the child's development. Public Law 99-457 and The Individuals with Disabilities Education Act have also led to the development of community systems for tracking of high-risk infants and resources for referring infants and young children for intervention. The emphasis on earlier identification creates the opportunity to provide the benefits of early intervention, but also poses greater challenges in the sphere of screening. Parents expect their pediatricians to give them guidance on developmental issues, but will turn to other community systems if the pediatrician does not fill this role. Children and families are best served when pediatricians' screening efforts are coordinated with the tracking and intervention services available in the community.

ISSUES IN METHODOLOGY

Delays or deviations in development may come to the attention of professionals and parents because the child is known to have risk factors by history, has physical findings or medical conditions likely to be associated with delays, or manifests delays at the time of observation. The first two factors are as useful in a very young child as in an older one, but some developmental delays are more difficult to assess early. A delay in a skill becomes evident only at the age when that developmental milestone is expected. For example, motor skills, which change rapidly in the first 2 years, are the easiest milestones to observe, but are the least predictive for future intelligence. Language skills are usually identified later but are better predictors of future intelligence and school performance.[4]

Developmental disabilities encompass a spectrum of problems of varying kinds and severity. Although

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broad agreement exists as to what constitutes clear-cut delay or deviation, there is not complete consensus among professionals, or between parents and physicians, as to the severity at which evaluation and intervention become appropriate and when deviations from norms are sufficient to warrant further clinical attention. The central dilemma for the pediatrician who screens patients is that identification must precede services, and the act of identifying a child as one who needs further assessment for developmental disabilities provokes anxiety in parents. This concern may create a tendency to identify only markedly delayed children, denying other children potential access to needed care.

The limited ability of infant tests, whether intended for screening or definitive diagnosis of intellectual functioning, to predict future function has led to controversy concerning their use. However, when physicians use only clinical impressions, estimates of children's developmental status are often inaccurate.[5] The advantage of screening instruments is that they state their norms explicitly, serve as a reminder to the pediatrician to observe development, and are an efficient way to record the observations.

The Denver-II, which is a successor to the Denver Developmental Screening Test, is a brief, validated test with which many pediatricians are familiar.[6] Although it has been criticized for having limited specificity and therefore risks overreferring, it has high rates of sensitivity and identifies delayed children correctly in a high proportion of cases.[7] Because the Denver II is intended to be used in the context of a process that includes other sources of information and multiple points in time, it is a useful part of the screening. The Early Language Milestones is another instrument suitable for office screening that was designed for identifying delays in language in children less than 3 years of age.[8] A recent review of commonly used screening instruments is available.[1] Although there is still a paucity of adequately validated tests that are brief and can be used for infants, the growing interest in assessment of infants and young children will likely result in the development of new instruments and methods.

Because the screening process selects those children who will receive the benefits of more intensive evaluation or of treatment after evaluation, all children should be screened for developmental disabilities. Screening is not the same as evaluation, diagnosis, or planning of treatment and represents the first step leading to a multidisciplinary evaluation. In the optimal situation, each child should have a defined medical home for primary care, and screening procedures should be incorporated into the ongoing health care of the child.

SCREENING PROCESS

Essential components of the screening process are as follows:

- Sensitive attention to parental concerns
- Thoughtful inquiry about parental observations
- Observation of a wide variety of the child's behaviors
- Examination of specific developmental attainments
- Use of all encounters for observing and recording developmental status
- Screening of vision and hearing to rule out sensory impairment as a cause of the delay
- Observation of parent-child interaction.

REQUIRED SKILLS AND PROCEDURES

To screen for developmental disabilities and intervene with the identified children and their families, the primary pediatrician must have the clinical skills and institute the procedures listed below:

1. Maintain and update her or his knowledge about developmental issues, risk factors, screening techniques, and community resources for consultation and intervention
2. Acquire skills in the administration and interpretation of a formal developmental screening technique
3. Develop a strategy to provide periodic screening in the context of office-based primary care, including the following:
    - Developmental screening of all children in the practice
    - Recognizing abnormal appearance and function during health care maintenance examinations
    - Recognizing high-risk medical and environmental situations while taking routine medical and social histories
    - Actively seeking observations and concerns from parents about their child's development
    - Recognizing troubled parent-child interaction from history or observation
    - Performing periodic rescreenings of practice populations to discover the possible emergence of new risk situations or the child's difficulty in meeting more advanced developmental expectations
4. Maintain updated information on existing community resources for serving infants and children at risk for, or with, developmental delays and their families;
5. Maintain linkages with these resources and coordinate patient care with them;
6. Increase parents' awareness of developmental disabilities and of resources for intervention by such methods as display and distribution of educational materials in the office; and
7. Be available to families to interpret consultants' findings.

Ongoing involvement with the family permits the pediatrician to respond to parental concerns about the child's development when such concerns exist. When parents are not aware of a delay that is present, the pediatrician can guide them toward closer observation of their child and thus enable them to recognize the delay. Referral for evaluation and services can take place only after the pediatrician has succeeded in this challenging task. At that point the pediatrician's role shifts to one of involvement in the evaluation as appropriate, referral to available community resources for intervention and family support, assistance in understanding the evaluation results, assessment and coordination of services, and monitoring the child's developmental progress as part of the ongoing pediatric care.

CONCLUSION

Early identification of children with developmental disabilities can lead to treatment or amelioration of the severity of a disability and its impact on the functioning of the child and family. Because developmental screening is a process that selects those children who will receive the benefits of more intensive evaluation, or of treatment, all infants and children should be screened for developmental disabilities, otherwise some may be denied access to needed care. Successful early identification of developmental disabilities requires the pediatrician to be skilled in the use of screening techniques and of developmental surveillance, to actively seek parental concerns about development, and to create linkages with available resources in the community. Because community systems vary from one locality to another and may change over time, the physician's information must be updated on a regular basis. Children and families are best served when the primary pediatrician providing health supervision services collaborates with the tracking and intervention services available in the community.

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AMERICAN ACADEMY OF PEDIATRICS

Provision of Related Services for Children With Chronic Disabilities

(RE9339)

Committee on Children With Disabilities

Since 1975 all children with disabilities specifically delineated by law have had available to them "a free, appropriate public education that includes special education and related services to meet their unique needs." This access has been made possible by the passage of Public Law 94-142,[1] The Education for All Handicapped Children Act of 1975. This law was amended in October 1990 with passage of Public Law 101-476, The Individuals With Disabilities Education Act (IDEA). Part B of Public Law 101-476 primarily details the identification and provision of services for children with disabilities. Unfortunately, the implementation of Part B of this law has been limited for many children by a number of significant and complex issues.

The term "related services" as currently defined in Part B of the IDEA includes the following:

> . . . transportation and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation and social work services, and medical and counseling services, including rehabilitation counseling, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education.

Health care providers frequently view the related services listed above as medically necessary and/or helpful for children with disabilities without the proviso that these services must be necessary for special education. This difference in perspective and interpretation by pediatricians and parents often leads to misunderstandings, frustrations, conflicts, and problems in the development and implementation of related services within school programs for children with disabilities. To best serve children with disabilities and their families, pediatricians need to be familiar with these issues, their legal basis, and the special educational process and system.

Providing related services presents significant opportunities for the children served and challenges for the educational system. With an increasing number of children with chronic diseases and disabling conditions entering the school system and the increasing complexity of these conditions, many issues and problems have developed. The availability of services, designation of responsibility for their payment and provision, and conflicting legal imperatives as well as other obstacles may ultimately prevent children from receiving potentially beneficial and needed services. Finally, the current trend of integration and inclusion of many children with a wide range of disabilities in "regular" classrooms and programs will make the provision of related services outside of traditional "special" educational settings a larger and more complex future issue.

The difficulties in implementation of Public Law 101-476 are as varied and complicated as the disabilities of the children involved. Among others, these problems include[2-4] (1) lack of clarity as to what circumstances should result in a child's exclusion from school for medical reasons; (2) uncertainty concerning responsibility for and/or administration of medical treatment in school; (3) inconsistencies in state and local guidelines and interpretations regarding who can and should prescribe the type and amount of physical, occupational, and speech therapies; (4) uncertainty about medical liability for therapies administered in school; (5) conflicting opinions concerning the propriety of some therapies being used for children; (6) concern about the rising cost of special education services and whether all treatment recommended in Individual Education Plans (IEPs) is warranted; and (7) the lack of provision of related services for children who may not require special education but who have chronic disabilities that impair their ability and readiness to attend and/or participate in school.

This statement primarily addresses the problem of children with chronic disabilities who may not require special education and the lack of provision of related services for them. For families and health care providers who believe that related services are desired and/or necessary, other legal justifications exist both within and beyond Public Law 101-476.

ISSUES

While initially it seems clear within the above definition that related services are those necessary to aid a child with a disability to benefit from special education, there are a number of additional conflicting issues. These conflicts exist as a result of additional amendments to IDEA, as well as Section 504 of the Rehabilitation Act of 1973, and a variety of court rulings.

In 1986, Public Law 94-142 was amended through the enactment of Public Law 99-457 (and its subsequent reauthorization, as Public Law 102-119, which included Part H programs for infants and toddlers with disabilities). The purpose of Part H is to strengthen incentives for "statewide comprehensive

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This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this policy statement do not indicate an exclusive ourse of treatment or serve as a standard of medical care. Variations, taking nto account individual circumstances, may be appropriate.

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coordinated multidisciplinary interagency program(s) of early intervention services for all infants and toddlers with disabilities and their families." In effect, implementation of Part H extends the availability of services to infants and toddlers with disabilities and their families from birth. Part H specifies the services to be those necessary to meet the developmental needs of each eligible child and the family needs related to enhancing the child's development in conformity with an Individualized Family Service Plan (IFSP). The IFSP is developed through evaluations assessing the following five domains: physical development; cognitive development; communication development; social or emotional development; and/or adaptive development. The philosophy behind providing these services is to maximize the developmental potential of these children and their families. This process recognizes the potential global benefits of these services, even if that child has deficits in a single domain (for example, physical development) and therefore may not require special educational or cognitive services.

While there are many similarities, significant inconsistencies exist between Part B and Part H in the requirements governing the provision of related services. Part H specifically includes interventions that under Part B are defined as related services without the restriction that the child receives special education (cognitive services). In fact, those services defined as related services in Part B are considered primary interventions in Part H. It makes little sense to consider services such as speech, physical, or occupational therapy important components of a program for a child younger than 3 years of age, but not necessarily important for a child older than 3 years of age unless the child's needs have changed. A change in the focus or location of the agency providing these services does not lessen the child's need for services. Children with chronic diseases and disabling conditions are best served by the acknowledgment of the consistency of their needs at all ages, rather than by the inconsistency of service delivery created by these statutes and regulations.

A further legal justification for the provision of related services without special class placement can be found in Section 504 of the Rehabilitation Act of 1973. This section prohibits discrimination on the basis of disability within federal and federally assisted programs. Regulations promulgated by the Department of Education have more broadly defined both the individuals covered by this act as well as the services that are to be provided. According to Section 504, all children should be provided with an appropriate education that "could consist of education in regular classes, education in regular classes with the use of supplementary services, or special educational and related services." Psychological testing and evaluation, counseling, physical and occupational therapy, medical services, speech pathology, audiology, and orientation mobility instruction are listed among the types of "developmental, corrective, and . . . support services" that may be provided to qualified individuals. Thus, Section 504 implies that children with special needs are entitled to appropriate modifications within their educational program to accommodate their special needs, regardless of whether their classroom placement is considered regular education or special education.

Court rulings have generally mandated that therapies recommended in the IEP be reimbursed by the educational system.[5] However, this has not precluded the application of Medicaid or other public funding to support medical service provisions for the disabled child. While private insurance carriers have generally declined to reimburse for therapies provided in the schools, in specific situations they can be responsible for payment of such services. The parents, however, have the right to decline to make claims against their insurance if it would create a realistic threat of financial loss by, for example, lowering the child's available lifetime medical benefits. Since the school systems have been bearing the responsibility for implementation of the IEP and funding most of the therapies, the educational authorities have increasingly been concerned with the responsibility for overseeing the delivery of medical care and other related services for disabled children attending public school. The assumption of these responsibilities has the potential to (1) increase conflicts with local physicians and other agencies responsible for health care delivery; (2) contribute to the disjointed nature of health care for children; and (3) result in unnecessary treatment at increased cost.[6]

The physician's role is currently defined as a related service and is interpreted to be diagnostic and consultative only. This interpretation becomes problematic in its failure to recognize the physician's role in the medical management, supervision, and program planning process for these children. The lack of physician input on treatment-related issues has posed the following important questions: (1) Does the health or the education system have the primary responsibility to oversee the delivery of health-related services in the school? (2) From what source should payment for such services be derived—educational funds, health-related entitlement programs, public health funding, or third-party insurers?

CONCLUSION

Just as a multidisciplinary approach is mandated and necessary in the initial evaluation of children to determine their eligibility for services within the educational system, it is necessary to maintain a comprehensive, multidisciplinary approach in the provision of these services. The inequalities in the interpretation and provision of services between and within states, and even school districts, present a cogent reason for clear, equitable interpretation of Public Law 101-476. Providing related services for children who may not receive special educational services and allowing for greater medical involvement may require new models of interaction and collaboration between the medical and educational systems. However, the increasing number of children with complex medical needs now within the educational system and the more frequent inclusion of these children within regular programs is

ırring the distinction between medical and educa-
nal services and regular and special educational
·vices. There is an increasing amount of data to sug-
st subtle impairments in the school performance of
ildren with chronic conditions who might other-
se appear to be intellectually unaffected.[7] The re-
irement of special educational services as the entree
· other services implies that schools are to provide
ly cognitive educational services and that children
not learn from, need, or benefit from other school
·vices and activities. This assumption is narrow and
:onsistent with current thought and the provision
a free and appropriate education for children with
sabilities because it does not adequately address the
ique and complex total needs of these children.
oviding these children with related services by uti-
ing a comprehensive approach to their chronic and
sabling conditions will afford them the best oppor-
nity to achieve their maximum potential.

RECOMMENDATIONS

The focus for services should be on the child with a disability and his or her specific needs, not the relationship of these services to the child's educational placement. The specific class placement should not determine the provision of related services in school. Health care providers need to be aware of the issues and inconsistencies in Public Law 101-476, Parts B and H, and Section 504 of the Rehabilitation Act of 1973. Such an awareness will enable them to serve as effective providers, resources, and advocates for children with disabilities and their families. This should help ensure that children with disabilities who do not have significant cognitive or achievement impairments, but would benefit from related services, would more likely have their total educational needs met.

It is important that physicians, especially pediatricians, seek representation on the local advisory and interagency committees that oversee programs for placement of children with disabilities in schools. This would allow physicians to take a more active role in the development and implementation of the IEP process.

To be effective in overseeing the provision of services, including related services, physicians should be well informed concerning the needs of children with disabilities. Educational opportunities about these issues should be made readily available for interested physicians.

The supervision of medical care and health-related services for children with chronic and disabling conditions is the responsibility of physicians and the medical community, regardless of the location or source of payment for these services. When this oversight responsibility extends to services provided by the school system, clear and careful collaboration and coordination with the educational authorities is necessary. Issues such as the source of payment, liability, location(s) for treatment, and the specific staff performing the treatment(s) should be resolved with the responsible state and local agencies.

5. The Academy recommends that the potential for the physician's role in the care of children with disabilities within the schools be expanded by revising and clarifying the definition of medical services. The child, his or her family, and the school may benefit by medical consultation to determine and supervise specific medical, nursing, and therapy needs of the child within the educational setting. Medical services should not be limited to diagnosing the child's medically related disabling condition that results in the need for special education and related services. Medical services should be defined to encompass diagnosis, evaluation, consultation, and the medical supervision of those other services that are by statute, regulations, and/or professional traditions the responsibility of a licensed physician.

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AMERICAN ACADEMY OF PEDIATRICS

Pediatrician's Role in the Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP) (RE9242)

Committee on Children With Disabilities

Approximately 10% of young persons between the ages of 6 and 17 years receive special education and related services.[1] An additional 750 000 neonates each year may have or be at risk for having developmental disabilities.[2] Therefore, pediatricians have many patients who have disabling conditions or are at risk for them.

Federal legislation requires each child identified as having a disability to have a written plan of service: an Individual Education Plan (IEP) for children aged 3 through 21 years or an Individual Family Service Plan (IFSP) for children aged birth through 2 years. The pediatrician is in a unique position to be involved in planning and providing care for both groups of children.

BACKGROUND

The Individual Education Plan

In 1975 Congress passed Public Law 94-142, the Education for All Handicapped Children Act, as an educational bill of rights to guarantee handicapped children a free and appropriate education. The law required that identification, diagnosis, education, and related services be provided for children 5 to 18 years of age. In 1977, the age range was extended to include children aged 3 to 21 years, with services for children aged 3 to 5 years remaining optional. Not only were these services to be provided, but states also were encouraged to seek out children who had not been served previously.

Conditions eligible under Public Law 94-142 include mental retardation, hearing deficiencies, speech and language impairments, specific learning disabilities, visual handicaps, emotional disturbances, orthopedic impairments, and a variety of other medical conditions categorized as "other health impaired." To be eligible for service under the legislation, a child must have an identifiable condition that has the potential to interfere with his or her educational process and normal school performance to the extent that special education services are required.

Other components of the legislation include the following provisions. (1) Each child must be evaluated by a multidisciplinary team. This team is responsible for designing an IEP that contains specific educational and therapeutic strategies and goals. All such plans are reviewed annually. (2) Each child must be educated in the least restrictive environment or with nonhandicapped students to the greatest extent possible. This criterion supports the concept of integration. (3) Related services, such as transportation, speech pathology, audiology, counseling, physical therapy, and medical services (for diagnosis only), shall be provided when deemed necessary by the evaluating team. (4) The parents' and the child's rights to "due process" shall be protected. This ensures the parents' right to be involved in educational decisions and to obtain redress through an appropriate hearing process when the team's decision is viewed as inappropriate or harmful. A 1987 American Academy of Pediatrics statement encouraged pediatricians to be aware of and partake in the process of formulating an IEP, reviewing it with parents, providing counsel, and coordinating the educational program with the medical treatment plan.[3]

The Individual Family Service Plan

In 1986 Congress enacted the Education of the Handicapped Act Amendments, Public Law 99-457.[4] The statute calls for "a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all handicapped infants and their families." The bill does not mandate services but does strengthen incentives. Almost all states have established a program for children aged birth through 3 years. These services are specified as "developmental services ... to meet a handicapped infant's or toddler's developmental needs in any one or more of the following areas: physical development; cognitive development; speech and language development; psycho-social development; or self-help skills." The purpose of these services is to enhance the development of handicapped infants and toddlers to minimize their potential for developmental delay. It also should reduce education costs to the public schools by minimizing the need for special education services after the youngsters reach school age, minimize the need for institutionalization, enhance the potential for independent living, and the families' abilities to meet special needs.

This statement has been approved by the Council on Child and Adolescent Health.

he law requires that each state create its own
inition of developmental delay as a basis for de-
nining eligibility for services. The pediatrician has
ignificant role in determining this eligibility by
ocating for a broad definition of developmental
ıy. If states participate, services must be provided
children already experiencing developmental de-
as well as for those diagnosed with a condition
t has a high probability of causing delay. In addi-
ı, states may elect to provide services to those
dren who are at risk of manifesting developmental
ıbilities at a later time.

ı major difference between Public Laws 99-457
l 92-142 is that Public Law 99-457 focuses on the
ıily. Under this law, the evaluation, assessment,
l planning take place with full family participation
l approval.

:hildren identified as 'at risk' receive a compre-
sive multidisciplinary assessment. The assessment
cribes the abilities and needs of the child and
ıily. Following assessment, an IFSP is created. IFSP
nents include statements on the following:

. the child's present attainments
. family strengths
. how to enhance development of handicapped infants and toddlers
. major outcomes expected, including criteria, procedures, and time lines to achieve specific goals
. specific early intervention services that will help the child and family
. projected dates for initiating services and their duration
. name of the case manager responsible for helping the family implement and coordinate the plan
. steps to help the child and family with the transition to school services at an appropriate time.

he statute specifies a wide array of other services,
the only health services included are those that
'necessary for the infant or toddler to benefit from
er early intervention services.' Diagnostic and con-
ative medical services may also be provided.

ИEDICAL ROLE AND RECOMMENDATIONS

here are several roles for the pediatrician under
ılic Laws 94-142 and 99-457.[5] Not every pediatri-
ı will be comfortable being engaged fully in each
:. However, all pediatricians should ensure that
ry handicapped child in their practice has access
he following services:

. Conventional health care.
. Screening and surveillance. The pediatrician should screen all children from the first encounter checking for risk of a handicapping condition or developmental delay. Pediatricians are in key positions to identify at the earliest possible age those children who may benefit from services under Public Laws 94-142 and 99-457. Pediatricians should provide screening and surveillance using a combination of methods best designed to take advantage of multiple sources of information.

3. Participation in assessment. A child identified through screening or observation as being 'at risk' for developmental delay should receive a comprehensive multidisciplinary assessment. The pediatrician has an important role as a referral source or, if more extensive participation is elected, as a member of a multidisciplinary team. Not all pediatricians may be comfortable participating in an in-depth assessment. However, all pediatricians should remain in communication with the assessment team.
4. Counsel and advice. During the assessment process, families will need a knowledgeable source of medical advice and counsel. Most assessment teams nominate a member as case manager to work with families. There should be a strong link between the assessment team and the primary care pediatrician and an open sharing of concerns between parents, the pediatrician, and the assessment team.
5. Creating the IEP and IFSP. Pediatricians who participate in the assessment process should be consulted when these documents are created. The assessment team and pediatrician can consult via various routes of communication, ie, in person, by telephone, or by mail. Such consultation is vital to preparing an appropriate and effective plan. When the pediatrician does not serve on the assessment team, he or she should review the plan developed, counsel the family, and prepare to comment as needed. The pediatrician should determine if the health-related services proposed are appropriate and sufficiently comprehensive. He/she should assist parents in performing their advocacy tasks when there is evidence of inappropriate planning. Ideally, when schools or educational agencies are involved in developing the IEP or IFSP, a pediatrician should serve as a member of the assessment team.
6. Coordinated medical services. When health services are part of the IEP or IFSP, they should be carried out by the primary care pediatrician or an appropriate subspecialist. Services and communication should be coordinated in those cases where the patients have complex medical needs involving several physicians or centers.
7. Advocacy. Pediatricians have many local and state opportunities to serve as knowledgeable and thoughtful advocates for improved community services for handicapped children. Pediatricians who select this role need to be aware of the structure of services in the community and the key persons who implement them.

CONCLUSION

Only by participating in interdisciplinary efforts for children with disabilities can the pediatrician focus on the needs of the whole child and improve the coordination of all forms of service and care.

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AMERICAN ACADEMY OF PEDIATRICS

The Role of the Pediatrician in Prescribing Therapy Services for Children With Motor Disabilities

Committee on Children With Disabilities (RE9629)

ABSTRACT. Pediatricians are often called upon to prescribe physical and occupational therapy service for children with motor disabilities. This statement defines the context in which rehabilitation therapies should be prescribed, emphasizing the identification and enhancement of the child's function and abilities. The statement encourages the pediatrician to work with teams including the parents, child, teachers, therapists, and other physicians.

Pediatricians commonly are asked to evaluate children with motor disabilities and to write prescriptions for physical and occupational therapy. Although many states require a physician's prescription for such services, many physicians have limited formal education about these therapeutic interventions.[1]

The spectrum of motor impairments affecting function in children and adolescents includes acquired spinal injury, traumatic brain injury, muscular dystrophy, arthrogryposis, spina bifida, and cerebral palsy. Many children with these conditions will benefit from physical or occupational therapy.

Although physical and occupational therapy are often components of the treatment programs for children with disabilities, no current evidence indicates that these therapies directly improve the specific motor impairment of the child.[2-6] Rather, therapists, working with the family, child, and teacher, promote a positive functional adaptation to the disability in the context of the child's developmental progress. In the last decade, some treatment programs for children with cerebral palsy and other motor disabilities have been carefully evaluated using meta-analysis, functional measures, and single-subject design methods.[7-12] Clear documentation of efficacy has continued to be elusive. This problem may in part reflect difficult issues of methodology associated with the study of therapeutic efficacy in children because of their changing maturation and the need to identify and measure appropriate outcome criteria.[2-4] A meta-analysis of 31 studies of early intervention found higher performance scores for children receiving services compared with a control group, with greater effects on overall developmental quotients than on specific measures of motor function. In one important study, physical therapy alone was found to be less effective than the incorporation of developmentally appropriate play and learning skills for motor-impaired children younger than 3 years.[12]

Given the multiple needs of the child with a disability, one therapeutic discipline alone rarely minimizes the effects of the disability. Well-controlled scientific studies with well-defined functional outcome measurements are therefore necessary to clarify the efficacy of physical and occupational therapy interventions for specific pediatric conditions. Issues such as the frequency and intensity of therapy services, the relationship to assistive technology, and rehabilitative and medical versus developmental models of therapy all require further investigation.

The pediatrician needs to understand the role of physical and occupational therapists in the overall treatment of children with disabilities and the therapeutic modalities that may affect functioning and otherwise help these children.[13-16] Physical therapists focus on gross motor skills, including sitting; sitting to standing in preparation for transfers; walking with or without assistive devices and braces; wheelchair propulsion; transfers out of the wheelchair (to a desk, toilet, or bath); negotiation of ramps, curbs, and elevators; and problem-solving skills for accessibility of public buildings. Physical therapists often have responsibilities for ordering equipment and assistive devices.[17-19] Occupational therapists focus on fine motor and visual motor skills that improve the integrated activities of daily living, such as dressing, grooming, toileting, eating, bathing, and writing.[20,21] Occupational therapy services may also include training in school readiness skills and the identification of techniques to help children compensate for specific deficits. Occupational therapists also provide expert consultation on certain technologies, such as environmental control units, augmentative communication systems, and adaptive toys.[20] If the child has motor problems severe enough to interfere with self-care or communication, the therapist may recommend a program to help the child compensate for the disability or adapt to it. Despite anecdotal reports of beneficial results in selected cases, however, neurophysiologic retraining programs that purport to alter the underlying neurologic disorder have little effect on functional skills and are inappropriate for children with motor disabilities.[5,6,22] Participation in sports can increase their endurance, self-esteem, and strength in a peer setting.[23]

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

The pediatrician's primary responsibility in writ- ; a prescription for therapy is to provide an accu- e diagnosis. Although often the cause of the dis- ility is not apparent, the physician must provide accurate description of the medical condition and ıether the child has a transient, static, or progres- e impairment. In addition to the primary neuro- ›tor disorder, all potential associated problems, :h as learning disabilities, mental retardation, sen- y impairment, speech disorders, emotional diffi- ties, and seizure disorders, must be identified, d treatment must be recommended. Children with :dical conditions that may be adversely affected by ›vement or other specific activities should have ›se conditions identified as precautions. Occupa- nal and physical therapists cannot make determi- ions on drug treatment and the children's medical ks during therapy. For example, weight-lifting ac- ity during therapy may be contraindicated in ne children with motor disabilities receiving long- m prednisone therapy because of the increased ‹ of fracture(s). Medical precautions may reflect diovascular parameters, seizure precautions, or ge-of-motion precautions.

he prescription for therapy should designate its ıls. Plans for physical and occupational therapy not depend solely on the diagnosis or age of the ient. They are most appropriate when developed ıddress specific functional goals in individual pa- ıts. The pediatrician should work with the family, ld, therapist, school personnel, developmental di- ıostic team, and other physicians to establish re- tic functional goals.[24,25] The pediatrician can help ıilies develop expectations of the goals of treat- nt and help them understand that treatment ınly assists in their adaptation to a condition ıer than changing the underlying neuromuscular blem. Pediatricians should be able to contact and expert consultation as in any other area of med- .e. Helpful resources include local and regional gnostic teams, early intervention and develop- ıtal evaluation programs, developmental pedia- ians, pediatric physiatrists, and pediatric neurol- sts.

herapy prescriptions should contain the child's gnosis, precautions, type of therapy, frequency of :apy, anticipated goals, and duration of therapy. ɔ examples of prescriptions include:

Diagnosis: cerebral palsy, spastic quadriplegia, se- ere dysphagia
Precautions: risk of aspiration with seizure
Type and frequency of therapy: speech therapy x/week × 6 mos
mprove oral motor stimulation and provide a lesensitization home program
Goal: improve oral phase of swallowing to in- rease oral intake.

Diagnosis: complete C-7 quadriplegia
Precautions: stable spine
Type and frequency of therapy: physical therapy x/week × 6 mos
ncreased range of motion, increased strength in vailable muscles, increased trunk control
Goal: transfers without sliding board independently, between level surfaces, and propels wheelchair in household.

Successful programs require regular communication among the therapists, educators, and prescribing physicians, with periodic reevaluation to assess the achievement of identified goals, to direct therapy toward new objectives, and to determine when therapy is no longer warranted.[26] Therapies that are individually tailored to meet the child's functional needs should be integrated with the educational and medical treatment plans with consideration of the needs of parents and siblings.

RECOMMENDATIONS

1. Pediatricians should be aware of all professionals and therapeutic modalities that have an impact on children with disabilities.
2. Pediatricians should be informed of and participate in setting functional goals for therapy.
3. Pediatricians should be involved with the ongoing process of evaluating therapy programs for children with disabilities.
4. Pediatricians should be aware of and use community resources, such as pediatric physiatry (rehabilitation medicine), local or regional diagnostic teams, and developmental pediatrics, to obtain expert consultation on therapeutic programs.

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AMERICAN ACADEMY OF PEDIATRICS

Why Supplemental Security Income Is Important for Children and Adolescents

Committee on Children With Disabilities

(RE9516)

The Supplemental Security Income (SSI) program for children is an important part of the federal government's social benefits program for children with special needs. The SSI program is a nationwide program administered by the Social Security Administration (SSA) that does the following:

- provides monthly cash payments based on family income,
- qualifies the child for Medicaid health care services in many states, and
- assures referral of SSI child beneficiaries into the state Title V Children With Special Health Care Needs program's system of care.

The SSA considers a child to be disabled if:

- the impairment–physical or mental, or chronic medical condition–is as severe as a condition that would keep an adult from working,
- the condition is expected to last a long time or is life threatening, and
- the child is unable to engage in the everyday activities that most children the same age can do.

Congress implemented the children's component of the SSI program in 1974 in recognition that disabled children who live in low-income households are among the most disadvantaged of all Americans and therefore deserve special assistance. The cost of caring for a child with special needs is an especially heavy burden for families with limited resources. The intent of the SSI program is to reduce the additional deleterious environmental effects that a low family income can have on the growth and development of the disabled child and thereby help these children become self-supporting members of society.

The SSI program provides cash benefits. Therefore, parents can decide how best to use these flexible funds to meet the needs of their child, such as for respite care, special equipment, or transportation to the physician's office. These benefits can also offset the potential income of a second working parent, thus allowing a mother or father to provide care for the child at home.

In addition, SSI eligibility automatically qualifies the child for Medicaid in many states. Because the income eligibility requirements for SSI are in general more liberal than those for Medicaid, the SSI program can provide disabled children access to the health care services that they might not otherwise be able to afford. In addition, all state Title V Children With Special Health Care Needs programs assist SSI child beneficiaries to access health and other needed supportive services that may be available through public and private programs.

The SSI rules for determining financial eligibility and disability are very complex. In addition, significant changes have been made recently to the eligibility criteria. The SSI program has never been well understood by many parents, health care providers, and program administrators at the federal, state, and local levels. Although approximately 910 780 children (0 to 21 years of age) were receiving SSI benefits as of June 1994, many more children would receive SSI benefits if they applied. This statement provides basic information about the SSI program and describes the roles that pediatricians can play in the SSI outreach, application, and disability determination processes.

FINANCIAL/RESOURCE ELIGIBILITY CRITERIA

The financial and resource eligibility criteria for SSI are extremely complicated. Although there are general guidelines, there are many exceptions. Therefore, the information provided here should be used as a general guide. The income limits for the SSI program are more liberal than some other federal assistance programs, such as Medicaid. For example, in 1994 a family with two parents in the home and two children in addition to the disabled child can earn up to $2800 per month and still be financially eligible for SSI; a family with one parent in the home and two children in addition to the disabled child can earn up to $2354. There are also limits on the amount of total assets (resources), such as jewelry, a savings account, or a checking account, that a family can have. The limit on assets is $2000 if one parent lives in the household and $3000 if two parents live in the household. When the family's assets are calculated, the following are not included: the family home (regardless of its value), household goods and personal effects up to $2000, and, generally, the family car. Additional information about 1994 income limits is included in Appendix A. These income limits are updated periodically.

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this policy statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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THE ZEBLEY DECISION

A significant change in the SSI program resulted from the February 1990 U.S. Supreme Court decision in the case of *Sullivan, Secretary of HHS, v Zebley*. In this decision, the Supreme Court ruled that the procedures used by the SSA to determine the eligibility of children for SSI were unconstitutional.

Before the Zebley decision, there was no assessment of a child applicant's "functional status" as part of the disability determination process. It was this omission that the Supreme Court cited as unconstitutional, because it discriminated against children by requiring them to meet stricter standards than adults to qualify for SSI. Thus, the child's functional status, in addition to diagnosis, became a critical factor in determining eligibility for SSI.

As a result of this ruling, the SSA has done the following:

- contacted and reevaluated children who had been denied benefits between January 1, 1980, and February 11, 1991, based on medical evidence alone (termed the "Zebley class"),
- developed new methods for gathering information about the medical condition and functional status of children,
- worked to improve the ways in which parents receive information about the program and apply for benefits, and
- developed methods for assessing the functional status of children.

The SSA methods for assessing functional status re now more applicable to children and take into onsideration the child's ability to perform expected, ge-appropriate activities; the impact of multiple onditions; and the child's need for support and ssistance from others.

DETERMINATION OF ELIGIBILITY FOR SSI

esumptive Eligibility

If a child has 1 of 13 specific impairments, he or she ay be found "presumptively eligible" for disability yments by the SSA field office staff. These 13 contions are as follows:

- amputation of two limbs;
- amputation of a leg at the hip;
- total blindness;
- total deafness;
- bed confinement or immobility because of a longstanding condition;
- stroke/cerebral vascular accident that occurred more than 3 months ago, with the child having continued marked difficulty in walking or using a hand or arm;
- cerebral palsy, muscular dystrophy or muscular atrophy, and marked difficulty in walking, speaking, or coordinating the hands;
- diabetes with amputation of a foot;
- Down syndrome;
- for a child 7 years and older, severe mental deficiency;
- enal disease requiring dialysis on a regular basis;
- human immunodeficiency virus infection; and
- birth weight less than 1200 g and less than 1 year of age.

A child can be presumptively eligible and receive SSI benefits for up to 6 months while the formal evaluation of eligibility is conducted. The decision of whether the child is presumptively eligible is based in part on the family's statements and on observations of the child by SSA staff members. The SSA staff cannot evaluate medical evidence. The pediatrician who treats a child with 1 of these 13 conditions should provide the parents with a statement about the diagnosis and the severity of the child's disabling condition. Parents need to know that they can request presumptive eligibility for their child based on this statement.

Disability Determination

The SSA does not make disability determinations directly. Rather, it has a contract with a state Disability Determination Services (DDS) agency to perform this function. State DDS agencies operate under federal regulations and instructions issued by the SSA. Once the SSA determines that the child is a U.S. citizen and appears to qualify financially, information about the child's disability and a list of additional sources of information are sent to the DDS unit. (Additional information about citizen/residency requirements is included in Appendix B.) The DDS agency uses a team comprised of a disability examiner and a medical or psychological professional to decide whether the child is eligible, based on the available written information.

The disability examiner must develop a complete medical and functional history for the child for at least the 12 months preceding the application for SSI. Staff of the DDS do not examine the child or meet with the child or family. Because the determination made by the state DDS unit is based on written information, it is important that pediatricians provide complete, detailed data in response to requests for information from the DDS.

Therefore, the pediatrician's medical report in support of a child's application for SSI should do the following:

- Refer to the SSA's childhood "Listing of Impairments" and use the specific terms and reference the specific clinical tests included in the listings. The listing contains criteria for evaluating the impairments of children (younger than 18 years), ie, mental and physical symptoms, signs, and/or laboratory findings, and includes 66 childhood diseases and disorders. These listings, however, have been criticized for omitting many disabling conditions. (A copy of the "Disability Evaluation Under Social Security" may be obtained from the SSA Office of Public Affairs, Public Information Distribution Center, P.O. Box 17743, Baltimore, MD 21235; telephone 410-965-0945, fax 410-965-0696).
- Include a medical history of the child (for at least

the previous 12 months).

- Provide complete, detailed clinical findings (eg, the results of physical, intelligence, developmental, and mental status examinations).
- Include complete, detailed laboratory findings (eg, blood pressure, radiographic films).
- Specify the diagnosis (statement of disease/injury based on signs and symptoms).
- Review treatment(s) prescribed with response and prognosis.
- State the probable duration of the impairment.
- Include an assessment of the child's physical or mental abilities to function independently, appropriately, and effectively in an age-appropriate manner and to perform age-appropriate daily activities.
- Describe the nature and limiting effects of the impairment(s) on the child's ability to function independently, appropriately, and effectively in an age-appropriate manner and to perform age-appropriate daily activities.

If the available information provided by those who treat the child is insufficient for determining disability, the DDS can arrange for a consultative examination at the SSA's expense by the child's treating physician, or, if the treating physician is unable or unwilling to conduct the examination, by an independent physician. On the basis of all the available information, the DDS follows a four-step process ("sequential evaluation") to make a determination. The steps of this process and the decision criteria are described in the Figure and given in detail below. The DDS then informs the SSA of the decision, which is given to the parents in writing. The process of determining disability can take 2 to 3 months. If the application is rejected, the parents have the right to appeal the decision.

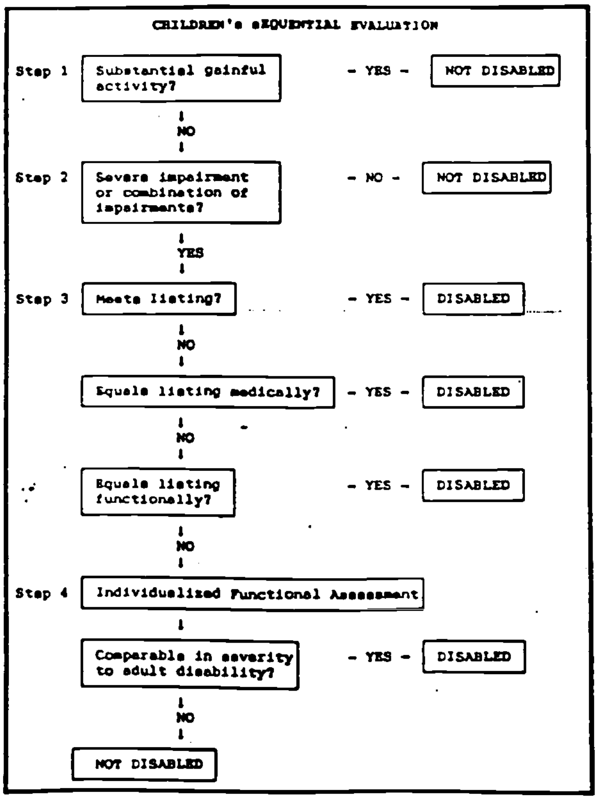

Figure. Children's Sequential Evaluation.

THE FOUR-STEP EVALUATION PROCESS

In step 1, the examiner determines whether the child is engaged in Substantial Gainful Activity, ie, work. If the applicant engages in Substantial Gainful Activity, the claim is rejected. If the child does not engage in such activity, step 2 is begun.

In step 2, the examiner determines, based on the available documentation, whether the applicant has a severe impairment or combination of impairments. Severe is defined as more than a minimal or slight limitation in a child's ability to function independently, appropriately, and effectively in an age-appropriate manner. If the examiner determines that the impairment is severe, or if there is doubt about the severity or the effect of the impairment on the child's functioning, step 3 begins. If the applicant has a minimal or slight limitation impairment, the claim is rejected.

In step 3, the examiner determines whether the child's impairment is the same as ("meets") or is either medically or functionally equivalent in severity to ("equals") one of the conditions on the SSA's "Listing of Impairments."

An examiner will find that a child meets a listing only when the symptoms, signs, and laboratory findings meet the findings included in the criteria for that listed impairment. If an examiner finds that a child meets a listing, then the child is determined to be disabled and is eligible for SSI benefits. If the child does not meet a listing, the examiner must determine whether the child's impairment is medically equivalent in severity to any listed impairment. If it is not, the examiner must determine whether the impairment is functionally equivalent in severity to a listed impairment.

An examiner must determine whether the available documentation indicates that a child's impairment or combination of impairments exhibits signs, symptoms, and laboratory findings that are of equal medical significance or severity to the listed criteria. If the child's impairment is judged to be medically equivalent to a listed impairment, he or she is classified as disabled. If the child's impairment is not judged to be medically equivalent, the examiner must determine whether the impairment is functionally equivalent in severity to a listed impairment. For example, according to listing 106.02D, a child who has had a kidney transplantation should be considered disabled for at least 1 year after the transplantation. Although not specifically listed, a child with disability from a heart transplantation should be found "equivalent to a kidney transplant because it has a similar impact on a child's ability to function in an age-appropriate manner" (Clark and Manes, 1992, chapter 12, page 6). The SSA rules and regulations (20 C.F.R. § 416.926a[d]) provide 15 examples of impairments that are functionally equivalent to those in the listings. If the child's impairment is judged to be functionally equivalent to a listed impairment, he or she is classified as disabled. If it is not, then the examiner must complete an Individualized Functional Assessment.

Step 4, the process of Individualized Functional Assessment, is the major modification to the SSI regulations by the SSA in response to the Zebley decision. The examiner must determine whether the impairments limit the child's ability, as much as they would an adult's ability, to function independently, appropriately, and effectively in an age-appropriate manner. The SSA's definition of "comparable severity" was expanded to take into consideration that if the manifestations of impairments in children are age related, then the evidence needed to evaluate disability appropriately is age related. The new SSI regulations specify the following age groups:

- newborns and young infants (birth to age 1 year),
- older infants and toddlers (ages 1 to 3 years),
- preschool children (ages 3 to 6 years),
- school-age children (ages 6 to 12 years),
- young adolescents (ages 12 to 16 years), and
- older adolescents (ages 16 to 18 years).

When evaluating the functional status of children aged 0 to 16 years, DDS examiners focus on the following:

- cognition (the child's ability to learn),
- communication skills (the child's ability to receive, understand, and express messages; with respect to speech, audibility, intelligibility, and efficiency of speech production),
- motor skills (the child's ability to use his or her body, hands, and feet in gross and fine motions),
- social skills (the child's ability to form, develop, and sustain relationships with other people on a personal and social basis), and
- personal/behavioral patterns, which refer to activities and behaviors entailed in the following: self-help, such as feeding and dressing; self-regulation, such as maintaining proper nutrition and sleep; self-improvement, such as increasing self-help behavior through learning new skills; self-protection, such as taking necessary safety precautions; and self-control, such as adapting to changes in the environment or an activity, or controlling impulsive or aggressive behaviors that could result in self-harm.

For evaluation of the functional status of infants, information should be provided about the child's physical and emotional responses to stimuli. For children older than 3 years, concentration, persistence, and pace in the completion of tasks should be evaluated. For older adolescents aged 16 and 17 years, school and work-like activities and the ability to function in a work setting are relevant factors.

As part of the Individualized Functional Assessment, the disability examiner must develop a complete medical and functional history for the child for at least the 12 months preceding the application for SSI. In determining the child's functional capacity, the examiner must also consider the impact of the following.

Chronic Illness. Detailed descriptive information should be provided if hospitalizations are so extended or frequent that they interfere with overall functioning, or if the frequency and/or effects of outpatient care significantly interfere with the child's daily activities.

Medication. Detailed descriptive information should be provided if medications and/or side effects cause or contribute to a child's functional limitations.

Supportive and Structured Settings. Detailed descriptive information should be provided as to how a child's symptoms are controlled or reduced by a highly structured or supportive environment, and whether the child can function independently, appropriately, and effectively in an age-appropriate manner outside of this environment.

Assistive Devices, Appliances, and Technology and Special Support Services. Detailed descriptive information should be provided if special devices or services provide some improvement without restoring adequate functioning, or if they themselves impose limitations.

Frequent and Ongoing Therapeutic Intervention. Detailed descriptive information should be provided if the multidisciplinary therapies that the child receives interrupt school or home activities and interfere with the child's development and age-appropriate functioning.

Although the information provided to the DDS by pediatricians is critical to the efficient, accurate determination of disability, pediatricians and other professionals generally do not describe a child's physical status and impairments using the criteria listed above. A physician's declaration that a child is disabled is not sufficient evidence for the DDS to determine a child eligible for SSI benefits. The SSA regulations require that the DDS perform a functional assessment of physically impaired children that relies on the pediatrician's providing information according to the factors listed above. Reports should use the specific terms and reference the specific clinical tests included in the "Listings of Impairments." In addition, when possible, formal test results regarding the child's functioning and development should be provided in terms of percentiles, percentages, standard deviations, or the fraction or percentage of the child's chronological age.

WHAT TO TELL FAMILIES ABOUT SSI APPLICATION, DISABILITY DETERMINATION, AND APPEALS PROCEDURES

Appendix C gives detailed information about how families can apply for SSI benefits for a disabled child.

CONCLUSION AND RECOMMENDATIONS

Pediatricians, individually and through state chapters of the American Academy of Pediatrics, can play a critical role in helping to ensure that all eligible children receive the SSI cash and associated benefits to which they are entitled. These efforts should include:

- providing information about the SSI program to families;
- increasing their knowledge about the SSI program and providing specific, detailed reports to the DDS in support of children's applications for SSI benefits; and
- advocating for better reimbursement and improved methods for providing reports to the DDS.
- The SSA has a variety of brochures designed to inform families about the SSI program. Physicians and state chapters should contact their local SSA field office to develop ways for making this information available through physicians' offices.

The SSA and state DDS units have designated the staff responsible for educating the professional community about the SSI program. The chapters of the American Academy of Pediatrics should invite the staffs of the SSA and DDS to participate in local and state-wide educational meetings and workshops. This will help ensure that the pediatric community is informed about the SSI program and skilled in providing medical evidence to support their patients' applications for SSI benefits. Such efforts can also help to develop working relationships between these agencies and the pediatric community.

Reimbursement for reports provided by physicians to the DDS is generally considered inadequate. State chapters can advocate for change in the reimbursement schedule and can also work with the state DDS unit to develop more efficient methods for providing reports. Some state DDS units have implemented a system whereby local physicians can call the DDS office and dictate their report on a child applicant. The DDS takes responsibility for transcribing this information and entering it into the child's application. Some state DDS agencies also provide report outlines to help focus the information on the pediatrician's report. Other agencies also use a professional advisory board. State chapters can advocate for the use or expansion of such a board to ensure that there is a good working relationship between the agency and the pediatric community.

These activities will help ensure that the SSI program is implemented more fully and that low-income, disabled children and their families receive the support and benefits they need.

APPENDIX A: SSI SCREENING—PARENT TO CHILD DEEMING

TABLE. Monthly Deeming Breakeven Points for Federal SSI Payment, Effective January 1, 1994, Through December 31, 1994*

No. of Ineligible CHILDREN	(All income must be below the following amounts) All Income Is Work Income 1 Parent	 All Income Is Work Income 2 Parents‡	 All Income Is Nonwork Income† 1 Parent	 All Income Is Nonwork Income† 2 Parents‡
0	$1908	$2354	$ 931	$1154
1	$2131	$2577	$1154	$1377
2	$2354	$2800	$1377	$1600
3	$2577	$3023	$1600	$1823
4	$2800	$3246	$1823	$2046
5	$3023	$3469	$2046	$2269
6	$3246	$3692	$2269	$2492

* Notes:
1. These income amounts refer to eligibility for the federal benefit only. Add the applicable state supplementation amount to these amounts.
2. All amounts assume that all children have no income and there is only one eligible child in the household. In any other case, refer to SSA.
3. For each additional ineligible child in the household (over six ineligible children), add $218 to the amount shown.
4. This chart does not work if the ineligible parent(s) has/have both work and nonwork income.

† Common types of income not counted in deeming:
1. Public income maintenance payments.
2. Income used to figure public income maintenance payments.
3. Foster care payments.
4. Food stamps, Department of Agriculture donated foods.
5. Income set aside under a plan for self-support.
6. Income used to pay court-ordered or Title IV-D support payments.
7. The value of in-kind support and maintenance.

‡ For a two-parent household, even if only one parent has income.

APPENDIX B: SSI CITIZENSHIP AND RESIDENCY ELIGIBILITY CRITERIA

To be eligible for SSI, a child must be a U.S. citizen or a naturalized citizen. The SSA defines a child as an individual who is younger than 18 years or younger than 22 years and a student, not married, and not the "head of a household." Children authorized to remain in the U.S. by the Immigration and Naturalization Service may also qualify. The child must also reside in one of the 50 states, the District of Columbia, or the northern Mariana Islands. Children living in Puerto Rico, Guam, and the U.S. Virgin Islands may be U.S. citizens but do not meet the SSI requirements for residency. The exception is children of military personnel who are assigned overseas duty.

APPENDIX C: WHAT TO TELL FAMILIES ABOUT SSI APPLICATION, DISABILITY DETERMINATION, AND APPEALS PROCEDURES

How to Apply

To apply for SSI benefits for a disabled child, a parent must complete, sign, and file a form that can be obtained by either

- visiting the local SSA field office or
- calling the SSA's toll-free number (1-800-772-1213) to make an appointment for a telephone interview.

Telephone Interview

If parents make an appointment for a telephone interview by calling the toll-free number, they should be contacted by staff of the SSA's telephone screening service. The interviewer will provide general information to parents about the medical, disability, and functional criteria that are used in determining eligibility for SSI. Information about disability criteria is provided to help parents decide whether they should proceed with the application process. The SSA prefers that parents use the telephone screening process because, according to the SSA, it is more efficient for both the parents and the SSA.

Parents need to know the following:

- the telephone line is often busy, but they should keep trying;
- the SSA interviewer will gather information about family income, financial resources, and the child's citizenship;
- on the basis of the above information, the interviewer will indicate whether it appears (or does not appear) that the child is financially eligible for SSI;
- the interviewer will ask whether they want to file an application for the child;
- they have a right to request and file an application even if it does not appear that the child qualifies financially;
- application forms will be sent by mail to their home;
- the telephone interviewer should not suggest that the child does (or does not) appear to meet the SSI disability criteria;
- the date of the telephone interview serves as the "protected filing date" and, if the child is found to be eligible for SSI, benefits will be paid back to this date;
- they should keep a record of all contacts with the SSA, including the date and the person with whom they spoke;
- the process of determining disability can take 2 to 3 months; and
- financial eligibility for young adults 18 years or older is based only on what they own and/or earn; family income/assets are not considered.

Applying at the SSA Field Office

If parents choose to go to a local SSA field office, they should call the local office or the toll-free number to make an appointment. This will ensure that an SSA staff person will be available to take the application and will reduce the amount of time the parents have to wait when filing an application.

If parents have a problem gathering all of the required information, they should still go to the SSA field office to begin the application process to establish a protected filing date. When the SSA has the needed information about family income and financial resources, financial eligibility for SSI will be determined.

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Suggested Readings

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Sullivan v Zebley, 88-1377 (U.S. Supreme Court, 20 Feb 1990)

AMERICAN ACADEMY OF PEDIATRICS

The Role of the Pediatrician in Implementing the Americans With Disabilities Act: Subject Review

Committee on Children With Disabilities (RE9623)

ABSTRACT. In this statement, the American Academy of Pediatrics reaffirms the importance of the Americans With Disabilities Act (ADA), which guarantees people with disabilities certain rights to enable them to participate more fully in their communities. Pediatricians need to know about the ADA provisions to be able to educate and counsel their patients and patients' families appropriately. The ADA mandates changes to our environment, including reasonable accommodation to the needs of individuals with disabilities, which has application to schools, hospitals, physician offices, community businesses, and recreational programs. Pediatricians should be a resource to their community by providing information about the ADA and the special needs of their patients, assisting with devising reasonable accommodation, and counseling adolescents about their expanded opportunities under the ADA.

Pediatricians need to be aware of the potential implications of the Americans With Disabilities Act (ADA). The ADA, passed in 1990, guarantees people with disabilities certain rights that help include them in all aspects of community activities. In fact, the broad definition of disabilities covered by this act results in a significant (and increasing) percentage of pediatric patients potentially being able to use its provisions to participate more fully in their communities. Pediatricians need to understand the relevant sections of the law to educate and counsel parents and adolescent patients and to connect them with appropriate resources.

ADA DEFINITION OF DISABILITY

The definition of a person with a disability for purposes of this legislation is someone who has a "physical or mental impairment that substantially limits one or more of the major life activities of said individual."[1] The ADA also covers individuals who were disabled previously or treated as if they were, even if currently they are not. The regulations do not supply a list of impairments but specify that any physiologic disorder or condition affecting one or more body systems is included if it interferes with life activities. This definition includes limitation in the "manner or duration" of the performance of a life activity and thus includes many common chronic diseases in pediatric patients, such as "contagious and noncontagious diseases, and conditions such as orthopedic, visual, speech, and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, diabetes, heart disease, specific learning disabilities, and HIV disease."[2]

Studies of the US National Health Interview Survey[3] have indicated that the percentage of children younger than 17 years identified with activity-limiting chronic conditions doubled (from 1.8% to 3.8%) between 1960 and 1981,[4] and data from the early 1990s indicate that rates have increased to more than 5%. This increase reflects a variety of factors, including increased survival of low birth weight infants, children with spinal cord and head trauma, and children with congenital disorders (eg, congenital heart disease or cystic fibrosis) previously associated with high mortality rates. In addition, an expanded view of the impact of common disorders (such as learning disabilities) in limiting major life activities has broadened the spectrum of children and adolescents potentially considered disabled under the ADA.

ADA PROVISIONS

The ADA seeks to change, over time, the way people with disabilities participate in their communities, both by prohibiting discrimination and by requiring "reasonable adjustments" of the environment. Although the greatest application of its provisions may be for adults with disabilities, children and especially adolescents with disabilities can benefit significantly from its protections. The ADA serves to empower and enable people with disabilities to overcome or circumvent barriers that are frequently artificial.

Title III of the ADA describes the various public facilities and accommodations that are included in its antidiscrimination prohibitions. In contrast to the provisions of section 504 of the Rehabilitation Act, which requires an individual with disabilities to be "qualified" for the particular activity, job, or service, the ADA requires reasonable accommodation unless: (1) there would be an undue burden to do so; (2) it would fundamentally alter the service provided; or (3) the individual poses a direct threat to the health or safety of others. This "presumption of qualification" suggests that the public world belongs to all people.[5] Although other specific components of the ADA relate to public transportation, public accommodations, and housing, this statement focuses on access to public programs and services, communications, and employment.

This subject review has been approved by the Council on Child and Adolescent Health.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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ACCESS TO PROGRAMS AND SERVICES

The provisions of the ADA apply to pediatric patients in many ways. The law prohibits discrimination against an individual on the basis of disability and the exclusion from participation in, or denial of the benefits of, the services, programs, and activities of a local government, including all public school system programs and activities. Because integration of individuals with and without recognized disabilities is fundamental to the ADA, state and local governments must provide services in the most integrated settings appropriate for the needs of the individual child, allowing interaction with children without disabilities to the greatest extent possible. Although specialized programs for children with disabilities may be offered, an individual with a disability cannot be denied the opportunity to participate in programs that are designed for individuals without impairments. For example, a child with a disability has the right to swim at a school pool without participating in a separate swimming program for children with disabilities.[6] In this situation, the school may impose legitimate safety requirements based on the actual risks associated with the particular child's disability, not on general presumptions about individuals with that type of disability. Furthermore, the wishes or preferences of teachers or children cannot justify denying children with disabilities participation in programs or activities that use the school swimming pool or gym. School systems must provide wheelchair access for children with disabilities, although it is not required that every school be wheelchair accessible.

COMMUNICATIONS

The telecommunications provisions of the ADA are particularly important for middle school children and adolescents with hearing impairments. At these ages, socialization skills frequently include telephone communication that connects them with peers without disabilities. Title IV of the ADA requires each state to have a telephone relay system that provides an interface between hearing and nonhearing and speech-impaired communicators, which increases the functional independence of impaired communicators and gives them a sense of belonging to their peer group.

ACCESS TO OTHER SERVICES

One important provision of the ADA is the requirement that individuals with disabilities have access to programs and services generally available to other members of the public. Such provisions affect almost all community businesses, such as restaurants, banks, retail stores, and medical offices. Programs and services must make needed accommodations, except when doing so creates an undue financial burden. Generally, freight elevators, back doors, or carrying the individual would not be considered effective access, unless used as a last resort and comparable to the access of individuals without disabilities. Expenditures for accommodations do not need to be exorbitant. The law specifically states that costs need to be reasonable in the context of the resources of the business. Furthermore, the majority of the adjustments and accommodations are inexpensive, require little or no building renovations, and can be readily accomplished.

EMPLOYMENT PROVISIONS

The ADA provides specific requirements regarding employment of people with disabilities. These requirements include physician offices and hospitals, among essentially all other employers, although the effective date of compliance varies according to the number of employees. These provisions benefit adolescents with disabilities by prohibiting discrimination when they seek part-time jobs during their school years and for career planning as they join the adult work force. Physician offices, health centers, and hospitals have expanded opportunities to hire employees with disabilities who can serve as role models for younger patients with disabilities using these services.

CONCLUSION

The ADA guarantees civil rights to children and adolescents with disabilities and their families and mandates changes to our environment to enable the equal participation and reasonable accommodation of those with disabilities. Pediatricians can increase community sensitivity to the provisions of the ADA by being advocates for their patients with disabilities. Because children learn to become autonomous through interactions with the environment (both physical and psychological), modifications in the community may need to be made to encourage and support learning for those with disabilities to achieve functional independence.[7] Further information about the ADA is available in the reference list,[8,9] and from the ADA information centers in each region. Also, a resource packet is available from the American Academy of Pediatrics Department of Health Policy and State Advocacy.

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SPECIALITY CLINIC VISIT: HOSPITAL FOR SPECIAL CARE

Location and Times:

Residents will be scheduled to attend the Hospital for Special Care for one half day (morning only) based on their schedule.

Hospital for Special Care	Contact Person:
2150 Corbin Avenue	John Pelegano, MD
New Britain, CT	Chief of Pediatrics
	(860) 827-4868

Format:

The resident will attend inpatient rounds and observe the care of children with developmental disabilities in an intermediate care facility.

Resident's Responsibilities:

Prior to attending the specialty clinic, the resident should read the enclosed articles regarding primary care of children with developmental disabilities.

During the clinic visit the resident should follow these procedures:

1. Inform the preceptor that he or she is there to observe and learn about the long-term primary care of children with disabilities.
2. Follow the attending physician on rounds and discuss acute as well as chronic care issues.
3. Complete the *Resident's Self Evaluation of the Specialty Clinic Visit.*
4. Provide the clinic Preceptor with the *Performance Rating by Preceptor Specialty Clinic Visit* form.

GUIDELINES FOR SPECIAL CARE SPECIALTY CLINIC VISIT

Purpose

- To gain a better understanding of how to provide care for children with disabilities and special health care needs, including: recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.

- To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.

Clinic Visit - Suggested Outline

- During this clinic visit the following issues should be discussed:
  - The service delivery model in the Hospital for Special Care Pediatric Unit.
  - The appropriateness of the physical environment on the unit.
  - The ability of patients to receive early intervention or special education services during their hospital stay.

- The nature of the relationship between hospital personnel and early intervention or special education service providers.
- How the **developmental** (as well as medical) needs of children are being met.
- How the social and emotional needs of children are being met.
- How hospital personnel attempt to involve family members in the care of and planning for their children.
- How hospital personnel interacted with each other during rounds (i.e., "team" behaviors observed).

RESIDENT SELF EVALUATION: SPECIALTY CLINIC VISIT HOSPITAL FOR SPECIAL CARE

Resident's Name:____________________

Date of Visit:____________________

Contact Person:____________________

1. Who was present during rounds?
   - ☐ Physician
   - ☐ Physician's Assistant
   - ☐ Nurse
   - ☐ Interns
   - ☐ Team Leader (RN)
   - ☐ Family Members
   - ☐ Respiratory Therapist
   - ☐ Other: ______________________________

2. List three issues involving the care of children with disabilities discussed during rounds:

3. In recent years the Hospital for Special Care shifted its service delivery model from long-term chronic care toward more temporary intermediate care, with the expectation that patients *will* improve and be transitioned back to the community. How do you view this trend?
   - ☐ positively
   - ☐ positively, with some reservations
   - ☐ with significant reservations
   - ☐ negatively

   Briefly describe your concerns or reservations:

4. List three advantages to the use of large open-space rooms in the pediatric unit.

5. List three disadvantages to the use of large open-space rooms in the pediatric unit.

6. Do any patients receive early intervention and special education services in the hospital? ☐ Yes ☐ No

7. Do any patients attend school in the community during their stay at the hospital? ☐ Yes ☐ No

8. What did you notice about the quality of interactions between hospital staff and patients in terms of how they were approached, touched, talked to, etc.?

9. Rounds can be viewed as a "walking" team meeting. Which behaviors did the team engage in? (check all that apply)

   ☐ brainstorming
   ☐ problem solving
   ☐ decision making
   ☐ goal setting
   ☐ delegating tasks
   ☐ deciding to seek outside consultation (through CCMC or other agencies)

10. List three possible barriers that could interfere with discharging a child to his or her home.

11. List three things you observed that show evidence that the hospital staff are attempting to meet the *developmental* (as opposed to medical) needs of children.

12. List three additional ways hospital staff could address the developmental needs of children.

13. Was the physical environment generally age appropriate for the children in terms of pictures, toys, family pictures, music, personal items, room decorations, etc.? ☐ Yes ☐ No

14. Did the physical environment appear to be comfortable in terms of bedding, lighting, temperature, etc.? ☐ Yes ☐ No

15. How do the children spend <u>most</u> of their time?
    - ☐ alone
    - ☐ interacting with adult staff
    - ☐ interacting with other children
    - ☐ interacting with adult volunteers
    - ☐ interacting with family members

16. What developmentally appropriate social and recreational experiences are provided for children in the hospital?

17. List three negative consequences of "institutionalization" or inpatient life for children in terms of their overall development.

18. Whether present or not, how is a child's family incorporated into rounds and treatment considerations? (check all that apply)

- ☐ discussion of family concerns, priorities, resources
- ☐ discussion of family's wishes for intervention
- ☐ attempts to involve family in child's care plan
- ☐ frequency of family visits
- ☐ discussion of barriers to family's involvement

19. Briefly describe how related services (Occupational Therapy, Physical Therapy, Speech and Language Therapy) are provided to children in the hospital.

20. How might technology needs interfere with a child's ability to receive related services?

21. List five different primary diagnoses for patients you observed during this visit.

22. Pick one child that you observed during rounds. Describe what impressed and/or concerned you about this child in terms of medical, developmental, social, and family issues.

23. The visit enhanced my understanding of issues children face in an intermediate care facility. ☐ Yes ☐ No

24. The visit provided me with an understanding of how the clinical team processes, shares, and uses information. ☐ Yes ☐ No

25. The visit allowed me to discover new ways in which a physician might be helpful to families and children. ☐ Yes ☐ No

26. I understand more about the challenges faced by families whose children are in an intermediate care facility. ☐ Yes ☐ No

27. I saw examples of doctors integrating medical, educational, and social services for the children. ☐ Yes ☐ No

28. I learned more about the benefits of professional collaboration in the care of children with disabilities. ☐ Yes ☐ No

29. I was satisfied with the preparation given for this clinic experience. ☐ Yes ☐ No

30. This visit was beneficial to me as a physician. ☐ Yes ☐ No

31. Overall, I was satisfied with the experience and knowledge gained from this visit. ☐ Yes ☐ No

32. In your own words please complete this phrase: This experience provided me...

33. What might you do differently in your practice as a result of this experience?

34. Did you have any difficulties during this experience? If yes, please describe.

35. Is there anything you would like to see added to or omitted from this experience?

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-7571

Thank you very much for your participation in the program visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: SPECIALTY CLINIC VISIT HOSPITAL FOR SPECIAL CARE

Preceptor's Name:____________________
Resident's Name:____________________
Date of Visit:____________________

The Resident:

1.	Demonstrated appropriate professional behavior.	☐ Yes	☐ No	☐ N/A
2.	Communicated clearly.	☐ Yes	☐ No	☐ N/A
3.	Actively listened.	☐ Yes	☐ No	☐ N/A
4.	Demonstrated an appreciation for the issues children face in an intermediate care facility.	☐ Yes	☐ No	☐ N/A
5.	Provided input about services available for children with special health care needs and their families.	☐ Yes	☐ No	☐ N/A
6.	Provided input about the resources available for children with special health care needs and their families.	☐ Yes	☐ No	☐ N/A
7.	Understood the challenges faced by families whose children are in an intermediate care facility.	☐ Yes	☐ No	☐ N/A
8.	Understood the process of information sharing among the clinical team.	☐ Yes	☐ No	☐ N/A
9.	Demonstrated an appreciation of the challenges in meeting children's developmental needs in an intermediate care facility.	☐ Yes	☐ No	☐ N/A
10.	Had done extra reading about issues that children and families face at intermediate care facilities.	☐ Yes	☐ No	☐ N/A

As a Preceptor, I:

11. Was satisfied with the quality of the resident. ☐ Yes ☐ No

12. Would be willing to host another resident. ☐ Yes ☐ No

Reliability:

13. The resident arrived at the scheduled time ☐ Yes ☐ No
If no, please explain.

14. The resident departed at the scheduled time. ☐ Yes ☐ No
If no, please explain.

15. Did you have any difficulties during this experience? If yes, please describe.

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
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Farmington, CT 06030
FAX: 679-7571

Thank you very much for your participation in the program visit and your honest feedback.

ADDENDUM* HOSPITAL FOR SPECIAL CARE SPECIALTY CLINIC

Related Articles:

General Principles in the Care of Children and Adolescents With Genetic Disorders and Other Chronic Health Conditions, Pediatrics, Vol. 99 No. 4 April 1997.

Family-Centered, Community-Based, Coordinated Care for Children With Special Health Care Needs, Pediatrics, Vol. 83 No. 6 June 1989.

Community Physician's Role is Case Management of Children With Chronic Illness, Pediatrics, Vol.84 No. 3 September 1989.

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

General Principles in the Care of Children and Adolescents With Genetic Disorders and Other Chronic Health Conditions

ABSTRACT. The intent of this statement is to describe the breadth of issues that have special pertinence to pediatricians who care for children and families affected by genetic disorders and other chronic health conditions. The Committee on Children With Disabilities believes that because these children are leading healthier and longer lives, pediatricians are the more highly qualified to serve them, by virtue of their training and experience, and to provide them a "medical home." This statement is designed to assist pediatricians in the treatment of these patients by describing their potential roles in relationship to their patients' changing needs, as they work with various members of ~~the~~ health care team and as they respond to the requirements of government agencies and various third-party payers.

During the last decade we have witnessed dramatic changes in the diagnosis and treatment of genetic disorders in children that have fundamentally altered the way pediatricians view such conditions. Children with genetic disorders now live longer, most into adulthood. Using the latest scientific information, pediatricians are in the unique position of assisting children who have genetic conditions to reach their full potential. This goal is best achieved by facilitating the integration of the child and family into the community while minimizing the effects of the genetic condition on the child's overall growth and development.

Individuals with genetic and other chronic health conditions and their families confront a seemingly endless series of stressors in their daily lives, many of which reflect having a chronic condition rather than being specifically related to the underlying disorder. These stresses may burden families emotionally, socially, and financially and may involve them with complex and often bureaucratic health, habilitation, education, and health insurance requirements. Pediatricians have a critical role in diagnosis, interdisciplinary planning, acute care delivery, and long-term treatment of children and adolescents with genetic disorders and other chronic health conditions.

Families play a central role in coordinating care and making decisions for the children. As the children mature, they may assume greater roles in the decision-making process. This process requires that pediatricians work with families to define and improve coping skills and to build a partnership that educates the parents, defines the care desired, and coordinates and assigns responsibility for the provision of that care. The role of each care provider should be clearly stated to the parent. Pediatricians have a key role in the provision of family-oriented, community-based services that recognize the following issues.

THE MEDICAL HOME

Lifelong chronic conditions are often characterized by periods of unexpected medical crises that may be life threatening, interspersed with periods of relative quiescence. Pediatricians should remain accessible through all these crises, providing a "medical home" for all such patients.[1-3] They often advocate for the family when dealing with third-party payers, such as Medicaid, the Civilian Health and Medical Program of Uniformed Services, and other insurance companies for managed care arrangements. Pediatricians should also provide continuity of care to mitigate the adverse long-term physical, developmental, educational, and psychosocial consequences of genetic and other chronic conditions.

CARE COORDINATION

Ongoing care often involves the services of a multidisciplinary team of health care professionals, which may include other medical specialists and surgical subspecialists, nutritionists, genetic counselors, public health and school nurses, physical therapists, occupational therapists, speech therapists, audiologists, psychologists, and social workers.[4] Services the team should provide include enhancement of coping skills, educational planning with the local school district, and access to care coordination and respite services. To fulfill their important growing role in managed care systems, pediatricians must become familiar with the skills offered by many disciplines and the role each professional plays in the care of the patient, and then they should help coordinate services for families so the needs of the patient are met in a seamless, cost-effective fashion.

TRANSITION

Increased vigilance by the pediatrician may be necessary during key periods of transition when new and sometimes difficult adjustments must be made by the child and family. Examples include the start of school, a job, or an intervention program; the changes faced during puberty and adolescence; and

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iving independently as an adult when health may leteriorate and continuity of care is potentially comromised.[5] The pediatrician should focus special atention on the family when an infant enters an early ntervention program, when a child begins school, vhen a child is hospitalized, as changes of puberty nd adolescence occur, and during the child's tranition into the world of higher education, employnent, and independent adult living. The process of hanging physicians—from pediatrician to an adult iealth care provider—may itself be difficult for the atient and family.

COMMUNITY-BASED SERVICES

The pediatrician should know which community ervice programs are available for all children (eg, arks and recreation and libraries) in addition to nportant special public and private programs that upport children with special health care needs. Vorking with the family and social services providrs, the pediatrician can help ensure that the family eceives the important services and information proided by voluntary agencies (eg, the Arc [formerly ie Association for Retarded Citizens], United Cereral Palsy Association, Cystic Fibrosis Foundation, rohn's and Colitis Foundation of America, Alliance f Genetic Support Groups, and National Organizaon for Rare Diseases), publicly sponsored programs g, early intervention programs, special education nd related services, Supplemental Security Income, nd mandated services of the state health departients through Title V of the Social Security Act), and atient information networks.[6] To maintain current nowledge about services available in the public and rivate sectors, pediatricians may keep in contact ith the local chapter or national office of the Ameran Academy of Pediatrics or their state Office of ervices for Children With Special Health Care eeds, or they may develop a relationship with a evelopmental pediatrics or chronic illness program a local medical center.

COMPREHENSIVE SERVICES

Children with special health care needs, especially iose with severe mental retardation, multiple disilities, or vision, hearing, or neuromotor impairient, may have less access than their peers to eeded general preventive health care services beiuse of their family's financial or socioeconomic atus, the limited availability of child care services, nited access to transportation, and the severity of e disability. These children and their families may ive difficulty locating health care providers who ive sufficient experience with or training in the mplex nature of these disabilities to provide them ith necessary services. Such children and families ay therefore need even greater attention from their pediatricians to ensure that they receive timely and appropriate developmental screening and evaluation, immunizations, sex education, and other counseling services.

In the last few years, impressive progress has been made in genetic services with the introduction of formidable new tools for screening, diagnosis, and treatment of a wide variety of inherited conditions. Because this progress will continue, pediatricians must stay abreast of the scientific advances while retaining their perspective on the art of the daily practice of medicine to meet the needs of children with genetic or other chronic health conditions and the needs of their families.

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Family-Centered, Community-Based, Coordinated Care for Children With Special Health Care Needs

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In June 1987, at a conference sponsored by the American Academy of Pediatrics (AAP) and the Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, the Surgeon General of the US Public Health Service, C. Everett Koop, MD, ScD, issued a report concerning children with special health care needs.[1] In the report, Dr Koop identified the following seven steps to improve access to care and quality of life for these children: (1) A pledge of a national commitment to all children with special health care needs and their families, (2) encouragement of localities in the building of community-based service systems, (3) assistance in ensuring adequate preparation of providers of care, (4) development of coalitions to improve the delivery of services, (5) establishment of guidelines to control costs of services, (6) encouragement and support of the development of adequate health care financing, and (7) continuation of research and dissemination of information.

Dr Koop also called for the establishment of a national agenda for families and professionals involved in the care of children with special health care needs to work together to improve the lives of these children and their families through a system of family-centered, community-based, coordinated care. In this paper, we will define what is needed to carry out this agenda, discuss some associated problems and solutions, and suggest the role that pediatricians can play.

DEFINITION OF THE NEED

Family-Centered Care

Family-centered care is the focus of philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special health needs. Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families. In this philosophy, patterns of living at home and in the community are promoted; parents and professionals are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care. To achieve this, elements of family-centered care and community-based care must be carefully interwoven into a full and effective coordination of the care of all children with special health needs.[2]

To accomplish the centralization of care within the family, pediatricians, other health professionals, and families must work together to achieve better understanding by parents and siblings of the illnesses concerned, to cope with the illnesses and their physical, psychologic, and social effects on the affected children and families, to operate as partners in the identification, delivery of, and receipt of appropriate services at the appropriate time, and to improve access to community services. All children could benefit from a family-centered approach to their health care, but it is especially beneficial to the 10% to 15% of children who have some form of ongoing health problem,[3] whether major or minor, short term or chronic. Included are the approximately 5% of children[4] with conditions that can cause a marked degree of functional impairment, such as spina bifida, rheumatic diseases, ma-

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lignancies, and hemophilia; the 6%[5] identified by the schools as having impairments such as mental retardation, sensory disabilities, and speech problems; and the 3.7%[6] who are limited in the amount or kind of usual activities of children their age in which they can participate. The first step in the process of providing the services these children need is the development of family-centered health services.

Community-Based Care

Children with special health care needs should have the opportunity to live at home and to share in the everyday family and community experiences that those without such needs take for granted. The challenge is to provide accessibility to the kinds of care that will make this possible. Such varied resources as special education, nutrition, vocational rehabilitation, financing, recreation, transportation, housing, and therapeutic services should not only be available but, as nearly as possible, based in the child's home community.

Special school services are among the most important community-based services. They provide alternatives to classroom teaching such as instruction for the home-bound and combined part-time classroom and home-bound instruction. Optimally, they also provide physical adaptations such as elevators, classes on the same floor, duplicate sets of books at school and at home, and additional time for changing classes. Additionally, special school services should provide adaptive physical education, individual educational plans, therapy in the school setting, transportation, school counseling, nutrition, and education of school personnel who deal with children with special needs.

Family to family networking as a community service to provide psychosocial support and information is a great, largely unmet, need for families of children with special health care needs. Although there are many parent groups focused toward the needs of specific diseases, provision of better local systems is needed. Some tasks involved in providing such systems in which pediatricians and family practitioners might logically become involved include identifying and screening parents to act as resource "parent pals," training parent pals in communication, acting with sensitivity, and other related issues, development of a resource directory for services and parent groups, and increasing professional and community awareness of family needs.

Another needed community-based service is an available team of health professionals organized to train families, school personnel, or others to use medical devices or equipment such as mechanical ventilators or catheters. Such teams should not only provide the necessary expertise, but they should also help classroom teachers and fellow students to be at ease with and accept the child being helped.

Coordinated Care

Implicit in the concept of coordinated care is the recognition that medicine currently has a complex array of people and services available for children with special health care needs. Appropriate, flexible, and reasonable ways must be found to link them together to provide maximum benefit to these children and their families.

In communities distant from tertiary centers, emphasis on local care by teams of health professionals supervised by a general pediatrician is a timely idea. According to MacQueen,[7] there are three groups of children who can be cared for as well, or better, in a community center or a level II facility as they can in a tertiary center: (1) the many children whose disorders are diagnosed and who are started on a regimen of therapy in a tertiary center but who can be observed by a cooperating and coordinated community service system; (2) those children whose disorders can be diagnosed and who are managed at a community-based center without ever visiting a tertiary center; (3) children who have survived their original problems who have new problems as a result of new diagnostic and therapeutic technologies.

EFFECTING A SOLUTION

Case Managers (Care Coordinators) and Community Health Teams

Services for children with special health care needs and their families remain fragmented and poorly coordinated. Inadequate communication among professionals, lack of an organized service system, lack of coordinating services, varying eligibility requirements for services and for financial aid, and insufficient or inappropriate fiscal resources all contribute to this problem. Research points to a need for more effective involvement of primary health care professionals in providing care and for improved linkages between primary and tertiary care services (D. K. Walker, S. L. Gortmaker, and M. Weitzman, unpublished manuscript, 1981).[8-10] Frequently, children with special health care needs are served only in tertiary settings that are basically inappropriate for achievement of a coherent approach to the health care of these children.

There is a pressing need for local case managers oriented toward focusing energies of not only the child's care but also of family decision making, thus promoting a sense of family rather than professional control. The case manager should be in the community and readily accessible. He or she can originate from a multitude of professions or agencies, varying with the resources of the community, and should be part of a community health team composed of appropriate, locally available health professionals. Its composition may vary not only in relation to the professionals available locally, but also with the needs of the individual child being served. The case manager and the community health team should work with and complement rather than supplant the care provided by the family's pediatrician or family practitioner. The case manager or coordinator's role is to help with medical management plans, access to and coordination of community-based services, family to family networking, educational aid, financial planning, and the provision of counseling and advocacy for the child and family. Concentration of the coordinating role in one member of the team, the case manager or coordinator, provides more efficient and effective use of health care resources and assists families and children to understand better, cope better, and receive appropriate services at the appropriate time. These services are not generally available now, one difficulty being the failure of insurance companies to cover them. Given the time and compensation, the family's pediatrician or family practitioner might in many cases be the best case manager. Both governmental and private insurance plans must be urged to insure and to provide adequate payment for the service of "case management."

Major issues that must be addressed by each developing community health team include providing appropriate services at the appropriate time by appropriate professional members of the team, providing compensation for the time of the team and the services of each of its members, facilitating the transition of older teenage and young adult patients to adult care settings, developing appropriate parent to parent networks, and developing effective ways of working with noncompliant families and patients. A close working relationship with the family's primary physician, preferably as a member of the team, and with appropriate tertiary centers is essential to success.

Tertiary Medical Centers

Community-based care must be linked to specialty care. It is not necessary, or possible, to have each component of specialty care and high technology available in every community in this country; it is necessary to find new ways to link families in communities to all of these services. Ways of forming new, more effective relationships between community teams and those providing highly specialized care in children's hospitals and university departments of pediatrics must be sought and developed, perhaps as consultative partnerships.

Coordination at and Between Various Levels of Care

Both horizontal and vertical coordination of care is essential to achieve the goal of family-centered, community-based, coordinated care of children with special needs. Horizontal coordination involves chiefly communication and coordination among the members of the community health team and between the members and other local resources such as schools, girl or boy scouts, little leagues, community swimming facilities, foster grandparents, and other organizations or individuals who might be of help to the child with special needs and his or her family. Vertical coordination involves communication and coordination among parents, the community health team, and secondary and tertiary medical facilities and resources. The case manager or care coordinator is an indispensable facilitator in this network. Parents may serve in this capacity if able and so inclined; they should always be involved in the initiation and finalization of any plan for their child.

Financing Coordinated Care

Few insurance carriers will pay for the services of a case manager or for time spent in planning conferences by health professionals, including physicians. The only health services that most carriers, including governmental agencies, will reimburse are those delivered directly to patients by physicians and occasionally by others, usually with the supervision or orders of physicians. Many children and families are either underinsured or uninsured, even for such services. Imaginative methods, backed by insurance and governmental funding, must be developed and used to improve financing for these children. Strategies such as insurance benefit packages to support ambulatory community-based services, more realistic Medicaid and Medicare insurance coverages, and high-risk pools or catastrophic coverages for "high-cost" children must be evaluated. Prospective payment plans to develop a comprehensive service package for children with special health care needs and their families should also be developed.

ROLE OF THE PEDIATRICIAN

The pediatrician's office should be the medical home for the child with special needs in his or her practice, because he or she is the logical initiator of virtually all medical services. For similar reasons, the child's pediatrician optimally should serve on that child's community health team. In a survey of a general pediatrician's practice,[11] it was shown that 13% of patient visits involved children with long-term illnesses or conditions. This indicates that a significant segment of pediatric practice is now devoted to such children and that pediatricians should adjust their own education and practices to provide optimal service to these children and their parents.

The role of the primary pediatrician in relation to children who have special health care needs and their families goes beyond that of providing primary care, yet it differs from the role of the subspecialist in a tertiary center. The challenge is to provide a true medical home for all such children in their communities to supply an ongoing source for continuous, comprehensive, coordinated health care. The community pediatrician, in establishing a medical home for children with special health care needs, will provide the following: medical management of the basic medical condition, as well as of incurrent illnesses, usual and special preventive health services; knowledge of and attention to problems peculiar to the child's handicap or disease; family/parent counseling; consultation with the public (or private) educational system; and communication and coordination with other professionals and agencies also serving the child and the family.

The last three provisions (counseling, school consultation, and agency communication and coordination) will be helped greatly by care coordinators and/or community health teams.

Pediatricians interested in providing family-oriented, community-based, coordinated care to children with special needs should equip themselves with the knowledge, skills, and resources necessary to establish a true medical home for these patients and their families. In Hawaii, Mitsunaga[12] observed that currently the pediatrician is expected to be more than an ordinary-illness doctor. Garrell[13] believes that participation in long-term care coordination must be a personal decision by each practitioner. He has prepared a self-assessment questionnaire to help the practitioner make this decision. A few pediatricians are limiting their practices to children and families with chronic illnesses and disabling conditions.

ISSUES OF CONCERN TO PEDIATRICIANS

Barriers to Overcome

Apparent barriers to participation in the care of children with special needs that must be overcome are as follows: inadequacy of fees that can be charged and collected to compensate for the time necessary to do the job; inertia in changing habits of practice; inadequacy of training in the long-term care of children with special health care needs; bewildering fragmentation of care of children with special needs among the many community services available; lack of knowledge of service resources available; lack of knowledge about comprehensive care of children with long-term conditions; lack of available resources to help coordinated care; and discouraging problems of territorial sovereignity, both within and outside of the medical care system.

Should All Pediatricians Participate in Coordinated Care?

The usual practice of primary pediatricians is concerned primarily with basic preventive measures and care of acute illness. Many pediatricians, therefore, have an acute care focus, are most comfortable with care of conditions in which a rapid response to therapeutic measures is shown, and become uncomfortable, impatient, or both with care that is time consuming and lacking in promptly visible results. Thus, to maintain the pediatrician's personal satisfaction and the satisfaction of those receiving the care, participation in the time-consuming process and slow progress of patients who need long-term coordinated care must be a personal decision by each practitioner.

Lack of Reimbursement for Extraordinary Time for Care

Children with special health care needs often require two or three times the amount of time per visit compared with the amount of time needed to care for children with the usual self-limited illnesses. Current reimbursement policies of both private and public sources of health care financing provide inadequate compensation to make full participation in the care of children with special health care needs economically viable for most practicing primary care physicians.

Relationship to Tertiary Centers

Many pediatricians feel excluded from the care of patients whom they have referred for tertiary care. Communication is poor, and a partnership does not exist. Pediatricians who practice significant distances from the tertiary center often are left "out in the cold" to coordinate services and provide care in between visits to the tertiary center, without the communication necessary to coordinate community-based services and to provide care that is appropriate.

Community Physician's Role in Case Management of Children With Chronic Illnesses

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ABSTRACT. There is general agreement that case management should be provided to children with chronic illnesses, yet it is not clear who should provide this service. A survey of physicians and parents of children with chronic illnesses was conducted to evaluate the practice and views of pediatricians and compare their assessments with those of parents. Surveys were mailed to 360 physicians and 519 families with response rates of 39% and 63%, respectively. The majority of physicians (74%) thought that the primary care physician should provide case management. When compared with parents, physicians underestimated the parental need for information about the child's diagnosis (8% vs 52%, $P < .001$), treatments (3% vs 54%, $P < .01$), and prognosis (30% vs 78%, $P < .01$). They also overestimated parental needs for information regarding financial aid (70% vs 58%, $P < .01$), vocations (78% vs 54%, $P < .01$), and insurance (62% vs 51%, $P < .05$). Four services ranked by need by parents in the top 10 were not ranked in the top 10 by physicians. Rural physicians noted that services were more difficult to obtain than did those in nonrural areas. The physicians surveyed made several recommendations for steps that could be implemented to facilitate their role as case manageers. If primary care physicians are to be effective case managers, alterations in the current system of care will be required including continuing education related to chronic illness, information about community resources, reimbursement for the time required to perform case management, and better communication between physician and parents. *Pediatrics* 1989;84:465–471; *case management, chronic illness, physician attitude, pediatric practice.*

Children with chronic illnesses have become a more important part of medical practice.[1-4] Although these children differ from each other in many ways, they share common characteristics. For example, no matter what the diagnosis, many chronically ill children require complex treatments from multiple health care providers. The daily burdens of care on the families and children result in major psychologic and social needs and increase the risk for psychosocial disturbances.[5,6] In addition, chronic illnesses affect the lives of children in a wide range of nonmedical areas such as school, recreation, and vocation.[7]

Ironically, the specialization that has improved the health and longevity of these children has resulted in fragmentation within the medical care system. Also, communication among the medical and other systems (such as educational) is often inadequate, access to services is still difficult for many families, and preventive services may be unavailable. This has resulted in crisis-oriented care, the duplication of some services, and the neglect of others,[8-10] which not only results in less than optimal care but also increases the burden on these families and children.

The importance of addressing all of the needs of chronically ill children and providing coordination of care has been recognized and is embodied in the concept of case management.[11] Comprehensive case management includes identifying and assessing the needs of children and their families (needs assessment), planning and arranging for medical and nonmedical services (comprehensive care planning), facilitating and coordinating services (including the training of community providers), monitoring services and patient progress (follow-up), and counseling, educating, training, and supporting patients and their families (empowerment). The successful implementation of case management requires knowledge about the patient and his or her family as well as about the systems involving them.

The concept of case management has also been incorporated into public policy. For example, by

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section 9508 of the Consolidated Omnibus Budget Reconciliation Act of 1985, funds are allocated to states for the provision of case management services within the Social Security Act (Medicaid).[12] According to Public Law 99-457, the Early Intervention Program for Infants and Toddlers with Handicaps, case management services must be provided to children who are part of the program.[13]

Case management is generally viewed as desirable; however, the issue of who should provide it for children remains unresolved. Some have suggested that the primary care physician is in an ideal position to provide this service for chronically ill children and their families.[14,15] Others have recommended that professionals including interdisciplinary teams, government officials, community health nurses, or tertiary health care providers should provide this service.[16-18]

The purposes of this study were to define the current practice and views of physicians regarding case management, compare their views with those of parents, identify barriers that prevent them from delivering comprehensive case management services, and determine the factors that would help them become more effective managers.

METHODS

The study involved samples of two groups, practicing physicians (pediatricians, family physicians, and general practitioners) and parents of children with chronic illness. Physicians were stratified by county from a list of primary physicians caring for children in the 13 pediatric specialty clinics at the Strong Children's Medical Center, University of Rochester, and were randomly selected using a table of random numbers. Questionnaires were mailed to 360 physicians. This was followed by a second mailing to those not responding initially. A subsample of nonrespondents was chosen and interviewed by telephone.

Parents were selected from the same pediatric specialty clinics at the University of Rochester/ Strong Memorial Hospital. They were stratified by clinic, and 25 to 40 families were randomly chosen from each setting (varying with the size of the clinic). Questionnaires were mailed to 519 families. This initial questionnaire was followed by a second mailing.

The two self-administered questionnaires used in this study were pretested with subgroups of their respective samples. The questionnaire for physicians was designed to assess the status of case management in their practice, the factors determining their decision to be case managers, the barriers preventing them from being effective case managers, and the interventions that would facilitate their role as case managers. In addition, questions parallel to those used in the parents' questionnaire were asked to elicit the physicians' views regarding topics related to chronic illness (such as the availability and importance of services, adequacy of information, and communication and coordination).

Questions regarding the parental instrument were adapted from the form developed by Deborah K. Walker for Project SERVE[19] and were part of a regional needs assessment. In the questions, parents were asked their views regarding topics such as the availability and need for services, adequacy of information, and communication and coordination within the health care and educational systems. For areas of the questionnaires where parents and physicians were used to rate or rank items (such as those shown in Tables 1 through 5), they were provided with a list of items as well as blank spaces in which to add their own items. Items entered by the respondents were then categorized. Statistical analyses of the data (*t* tests and analysis of variance) were performed using Statistical Package for the Social Sciences (SPSS).

RESULTS

A total of 115 physicians responded to the questionnaire. Of the original sample, 67 were either taking an extended vacation, had moved, had died, or were no longer in practice (and were therefore excluded from the analysis), for an initial response rate of 39%. The telephoned replies of 10 physicians who did not answer the mailed questionnaire were included in the data analyses. The survey was mailed to 519 families attending the specialty clinics; 327 (63%) responded.

More than half the physicians (58%) had primary pediatric practices, 30% were general practitioners and family practitioners, and 12% were pediatricians in hospital-based practice; 45% of the physicians came from the single urban county in the region (Monroe County, home of Rochester); the remainder came from rural counties. Nonrespondents were more likely to be general and family practitioners (63% vs 30%, $P < .01$) and to be from rural areas (73% *vs* 55%, $P < .05$).

When asked who they thought should be the case manager for children with chronic illness, the physicians replied as follows; community physician, 59%; parents, 20%; specialty clinic or physician, 15%; community health nurse, 4%. Of those physicians who answered "parents," 73% thought that the community physician should assist parents, 16% believed that the specialty clinic or physician should, and 8%, the community health nurse. Thus, 74% of those surveyed believed that the community physician should be the primary person to provide or assist in the provision of case management to these children. There were no statistically significant differences in these percentages by type of practice (pediatrics, family practice) or county of residence (urban vs rural). The respondents noted that, at that time, 36% of the chronically ill children in their practice had case management provided by the community physician, 24% by the parents, 24% by specialty clinic or physician, and 3% by the community health nurse.

When asked for what percentage of their patients it was clear who was providing case management, the respondents noted that for 51% of their patients it was unclear who was providing these services. The physicians rated factors that were most important in determining whether or not they would be willing to provide case management using a scale from 1 (not at all important) to 5 (extremely important). As shown in Table 1, the child's diagnosis, severity of condition, and the resources available in the specialty center were the three most important considerations. For general or family physicians, the diagnosis and severity were more important considerations (4.6, and 4.5, respectively) than they were for the pediatricians (4.2 and 4.1, respectively, $P < .05$). In Table 2, the perceived usefulness of various sources of information in helping physicians perform case management is shown. With a scale from 1 (useless) to 5 (extremely useful), reports from specialty clinics were rated the most useful.

Physicians were next asked to rank potential barriers to the provision of case management using a 5-point scale in which 1 was "not at all a barrier" and 5 was "a major barrier." As shown in Table 3, for those who believed that someone besides the community physician should provide case management, lack of time, unfamiliarity with resources and new technologies, and lack of payment were perceived as being much greater barriers. These relationships held for all practice types.

When asked what factors would be important in facilitating their role as case managers, physicians rated better communication with the specialty clinic or physician as the most important (Table 4). There were no significant associations between these ratings and demographic factors or preference for case manager. Parents rated specialty clinics (4.1 of a possible 5) as being better informed about community services than were community physicians (3.3) or schools and preschools (2.6, $P < .01$ for all comparisons). Physicians rated these in the same order (3.9, 3.4, and 3.2).

TABLE 1. Physicians' Rating of Factors Considered Important in the Decision to Be Case Manager*

Factor	Rating
Diagnosis	4.4
Severity	4.3
Resources available in specialty area	4.0
Personal relation with the family	3.5
Extent of nonmedical intervention needed	3.4
Time available	3.3

* Most important, 5; least important, 1.

TABLE 2. Physicians' Rating of Usefulness of Various Sources of Information to Provision of Case Management*

Factor	Rating
Reports from specialty clinics	4.6
Information from families regarding support systems	4.3
Reports from schools/preschools	4.0
Reports from community health nurses or therapists	3.8

* Most useful, 5; useless, 1.

TABLE 3. Physicians' Rating of Barriers to Provision of Case Management by Physicians Choosing not to Be Case Managers*

Barrier	Rating
Lack of time	4.0
Lack of knowledge regarding resources	4.0
Unfamiliarity with new technologies	3.6
Lack of payment	3.5

* Greatest barrier, 5; not at all a barrier, 1.

TABLE 4. Physicians' Rating of Adjuncts That Would Facilitate Their Role as Case Manager*

Adjunct	Rating
Better communication with specialty clinic/physician	4.5
Continuing education related to chronic illness	3.9
Information about community resources	3.8
Reimbursement for the time required	3.6

* Most useful, 5; useless, 1.

Parents rated specialty clinics and community physicians almost equally with regard to knowledge about their children's health (4.1 and 4.0, respectively) but rated the school system as less well informed in this area (3.2, $P < .01$ for both comparisons). They rated their community physician and specialty clinic as being equally accessible (4.4 and 4.4 of a possible 5). Both physicians and parents ranked specialty clinics or physicians (5-point scale) as better informed about community services (3.9 and 4.1, respectively) than either local physicians (3.4 and 3.3) or schools and preschools (3.2

and 2.6, respectively; $P < .05$ for both parents and physicians).

Physicians and parents ranked a list of 22 services by importance for the chronically ill child and degree of difficulty in obtaining them. A comparison of the rankings is shown in Table 5. Six items (respite care, parent support group, help with behavior problems, financial information or help, vocational counseling, and psychosocial services) were ranked as the 10 most important ones by both physicians and patients. However, four services ranked as the 10 most important to parents (with parents' and physicians' ranking shown in parentheses) were not listed among the 10 most important to physicians: information regarding community resources (1 vs 14), recreational opportunities (4 vs 13), summer camp (7 vs 19), and dental treatment (8 vs 16).

Physicians in rural counties ranked a number of services as more difficult to obtain than did those in Monroe County. These services included transportation, genetic counseling, parent support group, (all $P < .001$), day care, respite care, recreational opportunities, specialized dental treatment, and psychologic services ($P < .05$).

Physicians were then asked whether they thought families received sufficient information about several issues. As shown in Fig 1, physicians underestimated parental need for information about the child's diagnosis ($P < .001$), treatments being prescribed ($P < .001$), and prognosis ($P < .01$). On the other hand, as shown in Fig 2, physicians overestimated parental needs for information regarding financial aid ($P < .01$), insurance ($P < .05$), and vocations ($P < .01$). Physicians and parents rated communication within the medical system with regard to children with chronic illness on a scale from 1 (total inadequate) to 5 (excellent). Physicians rated the communication as fair (3.4), whereas parents rated it as poor (2.2, $P < .01$).

TABLE 5. Physicians' and Parents' Ranking of Services*

Service	Ranking	
	Physicians'	Parents'
Respite care	1	9
Day care	2	21
Parent support groups	3	3
Help with behavior problems	4	10
Financial information or help	5	2
After school child care	6	20
Assistance with physical household changes	7	15
Vocational counseling	8	6
Psychologic services	9	5
Homemaker services	10	22
Recreational opportunities	13	4
Information regarding community resources	14	1
Dental treatment	16	8
Summer camp	19	7

* In order of importance for the chronically ill child, each service is ranked from 1 to 22.

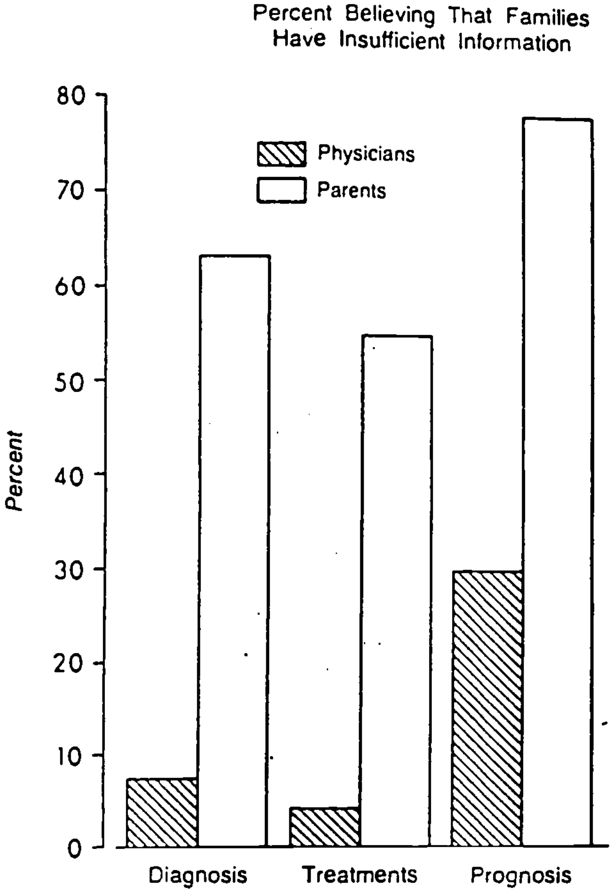

Fig 1. Comparison between physicians and parents regarding need for medical information.

DISCUSSION

The concept of case manager has been interpreted in a number of ways, such as the gatekeeper of a HMO or independent practice association;[20,21] the overseer for a third-party payer (such as an insurance company or government program (eg, Medicaid),[22] and the overall coordinator of care.[23] The goal of the first two roles is to reduce cost by avoiding unnecessary care, whereas the goal of the third is to match the needs of the child and family with available resources. Because of the complex, ongoing needs of many children with chronic illnesses, this third model should lead to better health than the other two and should ultimately also facilitate more efficient use of resources. The comprehensive case manager facilitates the delivery of quality care, provides links between systems, and helps families negotiate the complex array of services.

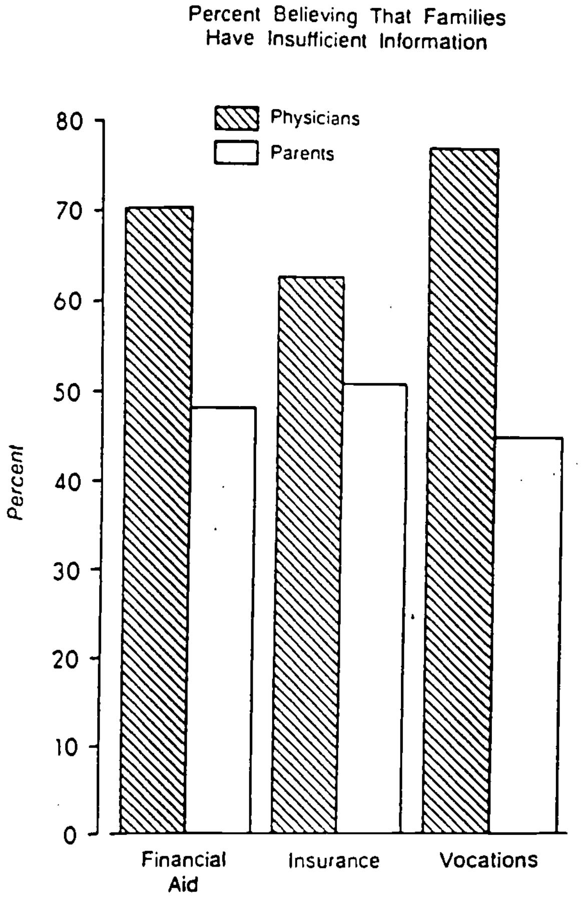

Fig 2. Comparison between physicians and parents regarding need for nonmedical information.

Case management may reduce the cost of care for some populations,[24-26] yet whether or not it improves the quality of care is an even more important question that has not been answered. Like many activities that have not been proven to be efficacious, effective or cost saving, case management has become a reality, especially because reimbursement has begun to be provided for it. Although the traditional role of the pediatrician (and other primary physician) involves aspects of case management, at least in a limited way,[27] the extent of intervention required by complex chronically ill children exceeds these traditional boundaries. Some have argued that primary pediatricians should provide case management for all children in their practices, whereas others believe that physicians do not have sufficient expertise or time to provide case management for complex patients.

The results of this study indicate that the majority of physicians surveyed (59%) believe that community physicians should provide case management for children with chronic illnesses, with an additional 15% believing that community physicians should be the primary facilitators for the parents. Parents, however, expressed the belief that specialty clinics are better informed than community physicians about community resources. This implies that either specialty clinics should provide case management or primary care physicians should become better informed if they want to serve as case managers.

Only 41% of the chronically ill children receiving care from community physicians who wanted to provide case management actually received case management from their physician. This finding supports the view that children with chronic illness are not receiving case management, even from physicians interested in performing this activity. The extent and quality of services actually received from physicians within the term "case management" were not addressed in this study. The physicians also noted that for 51% of their patients who did receive case management, the service was unclear. In 1974, Kanthor and his colleagues[8] maintained that case management was not being provided to children and that parents were unclear about the physicians' responsibilities in many areas of care. Little appears to have changed since that time.

Physicians in rural areas reported greater difficulties obtaining services such as transportation, genetic counseling, parent support groups, day care, respite care, recreational opportunities, psychologic services, and specialized dental treatment. This confirms the findings of others that children have less access to related services in rural than in urban areas.[28]

The provision of case management requires communication between the manager and the family as well as with other care providers. According to the parents in this survey, community physicians do not completely appreciate their viewpoint and are not providing sufficient information to them about their children's diagnoses, treatments, and prognoses. This information is basic to the physician-parent relationship and should be communicated before the physician considers other aspects of case management.

Physicians also overestimated the needs of parents' for information about financial aid, insurance, and vocations. Thus physicians believe that they are doing a better job than other professionals in providing information to parents. Parents do not share that view. In a similar fashion, physicians rated communication within the medical system higher than parents.

The 39% physician response rate was disappointingly small. The nonrespondents were more likely to be from rural areas and general practice (rather than pediatrics). If, as we suspect, the nonrespondents were less interested in the care of children with chronic illness, the report understates the problems of poor understanding between the community physicians and these families. For example, nine nonrespondents returned their questionnaires unanswered with notes attached stating that they saw so few children with chronic illnesses that they could not comment on the questionnaire.

SPECULATION

The large discrepancies between the perceptions of physicians and parents regarding the needs of these families are worrisome, because whoever provides case management should be able to assess accurately the needs of chronically ill children and their families. One potential approach to increase the sensitivity of physicians to the needs of this population is to provide increased exposure during residency—for example, having resident physicians spend time in the homes of these families and work with interdisciplinary teams to understand the nonmedical needs of the children.[29]

The physicians in this survey suggested other steps that could facilitate their role. These include improved communication with the specialty clinic, continuing education related to chronic illness, better information about community resources, reimbursement for their time, and increased availability of therapists and community health nurses. However, physicians must be certain that they are providing basic medical information about diagnosis, treatment, and prognosis to the families.

Although nonphysicians such as nurses and social workers have generally provided case management in geriatrics and mental health programs,[11,18,30] only 20% of the physicians surveyed in this study believed that other health care professionals would be appropriate case managers for children with chronic illnesses. Whether the quality of the case management provided by various professionals is comparable is uncertain. One of the problems some parents mentioned in their comments was that more than one person or group was listed as being case manager for their child but in reality managed only a single aspect of the child's care, eg, the educational program, insurance coverage, medical care, etc. One parent commented that she needed a case manager for her child's nine case managers.

Both physicians and parents who responded to the survey rated specialty clinics as being most knowledgable about community services. In addition, physicians rated specialty clinics as being of the greatest importance for both their current practice of case management and the facilitation of case management in the future. Because of the importance of specialty clinics, one strategy for developing case management services would be to have these clinics provide case management for a select group of children with chronic illness (such as those with the most complex problems). Another option would be to provide a specially trained person such as a community health nurse or social worker to act as a link between the primary care physician and the specialty clinic. Continuing education programs for community physicians sponsored by specialty clinics would not only increase knowledge of chronic illnesses but could also improve communication between the primary and tertiary providers and enhance the knowledge of the primary providers' of community resources.

For children with complex chronic illnesses such as spina bifida or human immunodeficiency virus infection, comprehensive case management requires much time.[31] In one study of case management in a mental health setting, the case managers averaged 30 minutes per each patient each day.[32] Some form of reimbursement for this time is needed to make it feasible for most community physicians to provide it.

In addition to the question of who should provide case management, a number of other questions need to be answered before large-scale programs of case management for children with chronic illness are established: Does case management for chronically ill children improve the quality of their care? Will it reduce long-term care costs for these children? What patients would benefit most from comprehensive case management? What system of case management works best? How many chronically ill children can a case manager effectively handle? Although much of what is done in medicine has become established without scientific evidence of efficacy, with the case management function, the opportunity to evaluate a concept before it becomes a widespread and accepted practice is provided.

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SPECIALTY CLINIC VISIT: ADAPTIVE EQUIPMENT

Location and Times:

Residents will be scheduled to attend the Adaptive Equipment specialty clinic for one half day based on their block schedule. Adaptive Equipment clinic takes place on Tuesdays and Thursdays from 1:00 PM to 5:00 PM at CCMC, fifth floor.

Format:

The resident will attend the Adaptive Equipment specialty clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time the resident should use any opportunity to talk with the patients, families, and team members. See *Specialty Clinic Experience: Guidelines for Observation.*

Resident's Responsibilities:

Prior to attending the Adaptive Equipment specialty clinic, the resident should read the attached summary of medical issues associated with the disabilities or conditions treated in this clinic and any other related readings.

During the clinic visit the resident should follow these procedures:

1. Inform the preceptor/family support person that he/she is there to observe and learn about the ***family's/child's point of view*** as part of the Children with Disabilities Rotation experience.
2. Be introduced (by the preceptor) to each family that is attending the clinic on this day.
3. Follow the patients throughout their entire appointment. For example, the resident should stay with the patients as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
4. Observe and interact with the patients, family members, and team members. *See Specialty Clinic Experience: Guidelines for Observation.*
5. Complete the *Resident Self Evaluation of the Specialty Clinic Visit.*
6. Provide the clinic Preceptor with the *Performance Rating of the Resident during the Specialty Clinic Visit* form.

SPECIALTY CLINIC EXPERIENCE GUIDELINES FOR OBSERVATION

Purpose

- To gain an understanding of adaptive equipment needs and concerns impact for various patients.
- To learn how adaptive equipment needs may impact the patient and his or her family in terms of their ability to participate in typical routines within the home, school, and community.
- To gain an in-depth awareness of how clinic visits are viewed through the eyes of patients and family members.

Observation of Specialty Clinic - Suggested Outline

During this specialty clinic, the resident should consider the following questions.

- What difficulties are patients having with their adaptive equipment?
    - How do these difficulties impact their functioning in home, school or work, and community settings?
    - Who is the person most likely to identify or describe the problems?
- What is the quality of communication between the professionals, the family members, and the patient?

  - Is the patient addressed directly?
  - Are suggestions for improvement elicited from the patient and family?
  - Are treatment *options* offered?
  - Are the patient and family involved in decision making?

- Do patients encounter any difficulties getting to the clinic (i.e., transportation, parking)?
- Does the adaptive equipment appear age appropriate?
  - Are there attempts to enhance the patient's independence?

- Are there any financial difficulties that could interfere with the patient's ability to acquire appropriate adaptive equipment?
  - Is insurance coverage adequate?
  - Are there restrictions, limitations, or timing issues imposed by the insurance company?

- What are the patients' and families' perspectives about the adaptive equipment clinic?
  - What are the perceptions of patient needs in home, school or work, and community environments?
  - Are the needs identified by patients being adequately addressed?

- What types of social supports do the patients and their families have?
- Do the patients and families appear to be at ease in this clinic?

❖ What role should a physician assume regarding a patient's adaptive equipment needs?

- How can a physician be an effective team member?
- How can a physician communicate with the treatment team?

RESIDENT SELF EVALUATION: SPECIALTY CLINIC VISIT ADAPTIVE EQUIPMENT

Resident's Name:____________________
Date of Visit:____________________
Contact Person:____________________

1. Who attended the clinic appointments for the patients you observed during this specialty clinic experience? (check all that apply)

   - ☐ Mother
   - ☐ Father
   - ☐ Siblings
   - ☐ Other family members:____________________
   - ☐ Physical Therapist from CCMC Adaptive Equipment Clinic
   - ☐ Home health care manager
   - ☐ Occupational Therapist or Physical Therapist from birth to three agency, school system, or other agency: (specify)____________________
   - ☐ Seating specialist
   - ☐ Vendors: (specify)____________________
   - ☐ Group home staff member or case manager
   - ☐ Primary care physician from the community
   - ☐ Physician/specialist from CCMC: (specify)____________________
   - ☐ Other:____________________

2. What were the first names, ages, and primary diagnoses of the patients you observed?

	First Name	Age	Primary Diagnosis
Patient A:			
Patient B:			
Patient C:			
Patient D:			

3. List the concerns or needs that were identified for each patient.

Patient A:

Patient B:

Patient C:

Patient D:

4. Who typically identified the problems? (check all that apply)
   - ☐ patient
   - ☐ family members
   - ☐ physician
   - ☐ service provider or case manager
   - ☐ other: ______________________

5. Who typically made suggestions for treatment and ways to address the identified problems? (check all that apply)
   - ☐ patient
   - ☐ family members
   - ☐ physical therapist from CCMC Adaptive Equipment Clinic
   - ☐ physician

- ☐ service provider or case manager

6. What role did the primary care physician assume?

7. In what other ways could the physician participate?

8. Which of the following behaviors did you observe of the individuals in attendance during these clinic visits? (check all that apply)
   - ☐ clear and effective communication
   - ☐ use of family friendly (non-jargon) language
   - ☐ a willingness to listen to the patients and their families
   - ☐ an openness to suggestions made by the patients and their families
   - ☐ a willingness to listen to other professionals
   - ☐ an openness to suggestions made by other professionals
   - ☐ a family centered care approach
   - ☐ a collaborative spirit
   - ☐ effective problem solving and decision making strategies

9. List the types or pieces of adaptive equipment that were being used by each patient.

<u>Patient A:</u>

<u>Patient B:</u>

Patient C:

Patient D:

10. Were treatment options given to the patient and family such as adaptation of equipment versus medical procedures/surgery; color or style of equipment, etc.? ☐ Yes ☐ No

11. Were efforts made to involve the patients in treatment suggestions? ☐ Yes ☐ No

12. Was the family and patient equal partners in the decision making process? ☐ Yes ☐ No

13. Were efforts made to get feedback from the patients regarding comfort or effectiveness of the adaptations? ☐ Yes ☐ No

14. Did the adaptive equipment appear age appropriate for each patient? ☐ Yes ☐ No

15. Did you have an opportunity to see any pieces of adaptive equipment that you had never seen before? If yes, please describe. ☐ Yes ☐ No

16. How were patients transported to the clinic appointments? (check all that apply.)

- ☐ car
- ☐ medical van
- ☐ other:________________________

17. Were there any transportation issues? (check all that apply)

- ☐ parking
- ☐ ability of van to fit into public parking garage
- ☐ availability of handicapped parking spaces
- ☐ wheelchair lift problems
- ☐ transferring or lifting patient into or out of the vehicle
- ☐ other:________________________

18. Were insurance and/or Medicaid issues addressed during any of these appointments? ☐ Yes ☐ No

19. Was coverage or reimbursement for adaptive equipment a problem for any of the families you observed? If yes, please describe. ☐ Yes ☐ No

20. Were there any evident limitations or restrictions imposed by insurance/Medicaid regulations? If yes, please describe. ☐ Yes ☐ No

21. What kinds of follow up were needed for the patients you observed? (check all that apply)
    - ☐ another clinic appointment
    - ☐ phone contact between the CCMC Physical Therapist and the patient and/or family regarding decisions about adaptive equipment
    - ☐ phone contact between the CCMC Physical Therapist and the patient and/or family to let her know how the new equipment is working
    - ☐ the need to order new adaptive equipment
    - ☐ consultation between the CCMC physical therapist and other health care or service providers
    - ☐ the need to explore insurance reimbursement issues
    - ☐ networking and resources for additional support for the patient and family (other patients with similar diagnosis, parent groups, organizations and agencies, etc.)
    - ☐ other:____

22. Describe any barriers that patients and families faced in terms of meeting their adaptive equipment needs.

23. In terms of adaptive equipment, what future needs can you anticipate for each patient you observed (e.g., transitioning to a new school or college, job-related changes, housing changes, etc.)?

    Patient A:

    Patient B:

Patient C:

Patient D:

24. Did the team encourage each patient's ability to use his or her adaptive equipment independently? ☐ Yes ☐ No

25. I understand more about the challenges faced by patients and families related to adaptive equipment needs. ☐ Yes ☐ No

26. The visit enhanced my understanding of the family's perspective of a clinic experience. ☐ Yes ☐ No

27. I understand more about the challenges faced by patients and families as they schedule and attend clinic visits. ☐ Yes ☐ No

28. I learned more about the benefit of families and professionals collaborating in the care of children with disabilities. ☐ Yes ☐ No

29. The visit allowed me to discover new ways in which a physician might be helpful to families and children. ☐ Yes ☐ No

30. I was satisfied with the preparation I was given for this experience. ☐ Yes ☐ No

31. This visit was beneficial to me as a physician. ☐ Yes ☐ No

32. Overall, I was satisfied with the experience and knowledge gained from this clinic visit. ☐ Yes ☐ No

33. In your own words please complete this phrase: This experience provided me...

34. What might you do differently in your practice as a result of this experience?

35. Is there anything you would like to see added to or omitted from this experience?

36. Did you have any difficulties during this experience? If yes, please describe.

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-7571

Thank you very much for your participation in the program visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: SPECIALTY CLINIC VISIT ADAPTIVE EQUIPMENT CLINIC

Preceptor's Name:____________________
Resident's Name:____________________
Name of Clinic:____________________
Date of Visit:____________________

The Resident:

1.	Demonstrated appropriate professional behavior.	☐ Yes	☐ No	☐ N/A
2.	Communicated clearly.	☐ Yes	☐ No	☐ N/A
3.	Actively listened.	☐ Yes	☐ No	☐ N/A
4.	Asked questions when he/she was confused.	☐ Yes	☐ No	☐ N/A
5.	Demonstrated respect for the patient's and family's beliefs, values, culture, and customs.	☐ Yes	☐ No	☐ N/A
6.	Obtained information from family members about their priorities, concerns, and desired outcomes.	☐ Yes	☐ No	☐ N/A
7.	Understood the challenges faced by patients and families related to adaptive equipment needs.	☐ Yes	☐ No	☐ N/A
8.	Understood the process of information sharing between the clinical team and the family.	☐ Yes	☐ No	☐ N/A
9.	Understood the benefit of families and professionals collaborating in the care of children with disabilities.	☐ Yes	☐ No	☐ N/A
10.	Offered helpful information or suggestions for the patient.	☐ Yes	☐ No	☐ N/A

As a Preceptor, I:

11. Discovered new ways in which the physician might be helpful to families and children and the clinical teams. ☐ Yes ☐ No

12. Was satisfied with the quality of the resident. ☐ Yes ☐ No

Reliability:

13. The resident arrived at the scheduled time. ☐ Yes ☐ No
If no, please explain.

14. The resident departed at the scheduled time. ☐ Yes ☐ No
If no, please explain.

Additional Comments:

As soon as possible, please return this form to:

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ADDENDUM* ADAPTIVE EQUIPMENT SPECIALTY CLINIC

Below are descriptions of the primary diagnoses carried by most patients who are seen in the Adaptive Equipment clinic. This is offered as a brief overview of these diagnostic categories, and the resident is urged to do additional reading as needed.

CEREBRAL PALSY

Cerebral palsy is a disorder of movement and posture due to damage to areas of the brain that control motor function. Cerebral palsy can occur before, during, or after birth and typically becomes evident in infancy or early childhood. The motor impairment may affect different parts of the body and may include:

- Hemiplegia - involving the arm, leg, and trunk on the same side.
- Paraplegia - legs only (rarely seen in cerebral palsy).
- Quadriplegia - both arms and legs, as well as the trunk and neck.
- Diplegia - legs more involved than arms.
- Double hemiplegia - arms more involved than legs, and one side more involved than the other.

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* *Adapted from: J. L. Bigge (1991).* *Teaching individuals with physical and multiple disabilities. New York: Macmillan Publishing Company.*

Involvement ranges from severe to mild. Factors include: a) level of independence in meeting physical needs; b) level of head control; c) amount of deformities that limit functioning or produce pain; and d) level of perceptual and sensory-integrative ability as they impact achievement of academic and age-appropriate motor skills.

In addition to the neuromotor impairment in cerebral palsy, there may be abnormalities of sight, hearing, speech, and sensation. Mental retardation and seizures may also occur with this condition.

In cerebral palsy, though the brain lesion does not progress with time, deformities can develop in the spine and extremities as the child gains length and weight. The most common descriptions of cerebral palsy include the area of injury within the central nervous system (pyramidal or extrapyramidal tracts); the muscle tone (hypertonia or hypotonia); the quality of muscle control (athetosis, dyskinesia, or ataxia); or mixtures of these.

Hypertonia is evident in approximately 60% of all cases of cerebral palsy. The motor cortex and spinal cord (pyramidal tract) are affected. Hypertonia is an increased stiffness that gradually causes limitation in range of motion and the development of muscle contractures. Deformities of the spine also develop with scoliosis (side-to-side curves) and/or kyphosis (posterior prominence; hip dislocation; and/or elbow, hand, knee, and foot contractures).

Hypotonia is a weakness, particularly in trunk and neck muscles. When mild to moderate degrees of floppiness persist through the first year without the emergence of spasticity or extrapyramidal (athetoid) involvement, generalized hypotonia is diagnosed. Many of the postural and movement mechanisms seen in hypotonic children are reminiscent of the infant at 4-8 months of age. Children with hypotonia are usually late walkers, balancing responses are sluggish, and overall motor activity level is low.

When the brain lesion affects the extrapyramidal tract of the central nervous system, **athetosis, choreoathetosis, or dyskinesia** results. Extrapyramidal involvement produces involuntary movements. The arms, hands, and facial muscles are typically more involved than the legs. Choreoathetoid movements are wormlike and writhing.

Ataxia is the rarest type of cerebral palsy, occurring in only 1% of cases. The cerebellum is the primary site of injury and the main feature is an inability to achieve coordination in balancing and hand use. The individual bobbles while standing and walking, and "overshoots," often missing the object he or she is trying to reach. Constant efforts to stabilize can result in the eventual development of a rigid quality of movement.

The diagnosis of just one type of cerebral palsy is rarely appropriate. **Mixed cerebral palsy** is most common because brain damage is often diffuse. Thus, it is typical to encounter a diagnosis such as "mixed spastic/athetoid quadriplegia, with an apparent underlying ataxic component."

A diagnosis of cerebral palsy generally indicates that a multidisciplinary approach to treatment and physical management is necessary. Services of a physical therapist, occupational therapist, speech therapist, nurse, special education teacher, and classroom aide may be required.

Typically, students with moderate involvement require the greatest proportion of direct therapy time in an attempt to raise the student's level of independence and to prevent deformity. For students with severe involvement, therapists can train classroom educators and aides in positioning techniques and strengthening activities that can be used daily to prevent deformity and pain, and to enhance participation

in classroom activities. Augmentative communication and power-driven mobility devices may also be required. Therapists then continually monitor equipment needs and provide consultation to the teachers. Students with mild impairment can usually be treated in groups with the aid of an adaptive physical educator who consults on a regular basis with the therapists and classroom teachers.

MUSCULAR DYSTROPHY

Muscular dystrophy is a hereditary disease characterized by muscle weakness that increases over time. There are several forms, of which the most common is Duchenne muscular dystrophy. Females usually transmit the condition to their male offspring, but are not affected themselves. The CPK enzyme (creatine phosphokinase) is elevated in the blood of those with muscular dystrophy.

Duchenne muscular dystrophy begins early in life, between the ages of 2 and 6 years, when the child is observed to have trouble climbing stairs and running. Weakness generally begins in the pelvic girdle muscles, but may occur first in the shoulder girdle muscles. Gradual loss of respiratory function is secondary to weakness of the abdominal and thoracic muscles. By age 10 to 14, walking usually ceases, and wheelchairs are required. Individuals with muscular dystrophy need increased amounts of physical assistance with some school activities and with most, if not all, activities of daily living as their disease progresses. When children with muscular dystrophy become wheelchair users, severe spinal curvature and contractures in the flexors of the hips, knees, ankles, and feet typically occur. Three months of sitting greatly reduces the likelihood that an ambulating child will walk again. A period of illness that requires bed rest can also reduce the child's functional level.

Individuals with muscular dystrophy often live until adolescence or young adulthood. In the final stages, there is an increased incidence of respiratory infections. Death is usually caused by heart failure due to the weakened heart muscles or respiratory failure caused by the weakness of the chest muscles. Individuals with muscular dystrophy experience the psychosocial difficulties of any terminal illness.

SPINA BIFIDA (MYELOMENINGOCELE)

Spina bifida, a condition present at birth, is a defect in the closure of the vertebral bodies of the spinal column. There are three classifications of spina bifida:

- Spina bifida occulta - This is the mildest form in which protrusion of the spinal cord or its covering does not occur; only a few vertebrae are effected. The defect is not externally visible other than the occasional hairy patch over the defect.
- Meningocele - In this form the spinal cord covering protrudes through the open defect in the spine.

- Myelomeningocele - This is the most common form of spina bifida, characterized by the protrusion of the spinal cord and its covering through the defective vertebral opening. Presence of a myelomeningocele results in varying degrees of paralysis and loss of sensation in the lower trunk and lower limbs. The higher the spinal defect, the more severe the neurologic and functional deficits, including loss of sensation, weakness, loss of bladder or bowel control, joint deformities, and spinal curvature. Many individuals with myelomeningocele have an associated **hydrocephalus** characterized by head enlargement, brain abnormalities, and seizures. Hydrocephalus is caused by blocked cerebrospinal fluid drainage. It may be congenital or develop later.

Treatment of myelomeningocele is initiated shortly after birth with surgical repair of the bulging sac. Physical therapy is useful for gait training and teaching the use of mobility aids. Patients with myelomeningocele may be able to ambulate independently with the use of braces and crutches or may be nonambulatory, requiring a wheelchair at all times. Perceptual and other learning disabilities, attention deficits, and emotional difficulties are often found in children with myelomeningocele. Students may also have deficits in sensation that impact their ability to process information from touch, movement, position in space, and motor experiences.

Effects of intraventricular hemorrhage and hydrocephalus on the long-term neurobehavioral development of preterm very-low-birthweight infants

Measures of intelligence, neuropsychological functions, academic skills, and behavioral adjustment were obtained at school-age from children born preterm with no hydrocephalus ($N=29$), arrested hydrocephalus ($N=19$), and shunted hydrocephalus ($N=17$), and a term comparison group ($N=23$). Most children also received concurrent neurological examinations and MRI brain scans. Results revealed significantly poorer neurobehavioral development in all four domains in preterm children with shunted hydrocephalus. Despite abnormal MRI findings in virtually all children with arrested hydrocephalus, significant differences between preterm children with arrested hydrocephalus and those with no hydrocephalns were largely in areas involving attentional and academic skills. Preterm children with no hydrocephalus tended to show poorer motor development relative to term children. Neurological abnormalities were restricted to children with spasticity in the arrested ($N=2$) and shunted ($N=10$) groups. These results highlight the importance of separating cases according to residual neurological and neuroimaging abnormalities in accounting for variations in the neurobehavioral development of preterm, low-birth-weight infants.

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Hydrocephalus is a potential complication in preterm, very-low-birthweight (VLBW) infants, representing a condition that increases the volume of CSF in the ventricular system. The increased volume leads to ventricular expansion and macrocephaly. The prevalence of progressive hydrocephalus requiring shunting has been estimated at 0.7% in North America (McCallum and Turbeville 1994), and 1% in Sweden (Fernell et al. 1993) from preterm birth cohorts identified from the late 1970s to late 1980s. Of preterm infants with intraventricular hemorrhage (IVH), 13% develop progressive hydrocephalus, with 6% requiring shunting (Dykes et al. 1989).

Hydrocephalus has deleterious effects on the preterm brain. Because of the expansion of CSF volume, the brain is compressed, with maximal initial effects on cerebral white matter. The corpus callosum is often stretched, leading to hypoplasia in which all corpus callosum structures are present but thinned. Parts of the corpus callosum, particularly the body, can be destroyed. Other white matter tracts (e.g. projection fibers) are stretched. Visual defects can result from damage to the optic tracts in the brain. The long-term consequences of severe hydrocephalus can include general cortical thinning, reduced brain mass, and cell necrosis in the gray matter (Del Bigio 1993).

The presence of hydrocephalus in preterm infants is most often associated with IVH. These hemorrhages, which occur in the germinal matrix and parenchyma of the brain, are not always associated with hydrocephalus. The most common classification of IVH (Papile et al. 1978) separates grades I and II IVH, in which the hemorrhage is present without ventricular dilation, from grades III and IV IVH, in which ventricular dilation and hydrocephalus are present. Although the incidence of IVH is declining (Volpe 1989), infants who develop grade III and IV IVH by definition will show progressive ventricular expansion, which in some cases requires shunting to regulate the flow of CSF. However, the ventricular expansion can also be treated with pharmacological interventions and spinal taps. These interventions may arrest the accumulation of CSF and the expansion of the ventricles. Since infants who show arrested hydrocephalus rarely receive neuroimaging ventricles normalize in these children.

The long-term neurobehavioral development of preterm children who develop IVH and hydrocephalus is not well understood. There are numerous studies of the development of infants with IVH up to 3 years of age. Although some early studies associated IVH per se with global impairment of developmental problems (Gaiter 1982. Williamson et al. 1982. Garcia-Coll et al. 1988). most studies showed that impairments in development were more apparent in those cases with severe and progressive IVH that lead to hydrocephalus (Dykes et al. 1989; Landry et al. 1984. 1988. 1993; Sostek et al. 1987). Dykes et al. (1989) reported no differences in the long-term outcomes of preterm children with progressive versus arrested hydrocephalus. However. Fernell et al. (1993) and McCallum and Turbeville (1994) observed significant morbidity in association with shunted hydrocephalus in this age range.

Studies of IVH in the 4- to 6-year age range are similar. Chapieski (1987) reported developmental deficiencies only in children with grades III and IV IVH and severe bronchopulmonary dysplasia in a well-controlled follow-up of the Landry et al. (1984. 1988) cohort. However. this study did not separate children with grades III-IV IVH according to the presence of residual arrested or shunted hydrocephalus. Similarly. Sostek 1990) reported that a major hemorrhage group (grades III-IV IVH) differed significantly from a minor hemorrhage group (grades I-II IVH) on components of the McCarthy Scales of Children's Abilities and indices of school readiness. Differences in motor. and perceptual-motor skills. and kindergarten readiness were also apparent between a term and reterm no-IVH group. In a study of 5-year-old children. eltzer et al. (1992) compared a term group with preterm roups who had minor (grades I-II) and major (grades II-IV) IVH. Both IVH groups differed from the term group n measures of verbal. perceptual-motor. preacademic. and emory abilities. In addition. children with major IVH tendd to perform worse in these skill domains. but were not signifiantly different from the minor IVH group in most omparisons. It was not apparent from Sostek (1990) or eltzer et al. (1992) whether children with shunts were includd or excluded in the IVH samples. It is possible that inclusion f children with shunted hydrocephalus would result in poorer evelopmental performances. presumably reflecting greater verity of hydrocephalus and the need for neurosurgical tervention. For example. Dykes et al. (1989) reported intellience test scores in the 75 to 80 range and a high rate of handiups in children born preterm who developed progressive drocephalus. However. developmental performance was not aluated in relationship to shunting.

There are no studies of the neurobehavioral development of eterm. VLBW children that specifically focus on IVH and drocephalus in the school-age range. Studies at older ages e important since epidemiological investigations of birth horts of VLBW and term infants clearly show a higher freuency of neurobehavioral abnormalities. and learning and tention disorders. in the VLBW cohorts (Broman et al. 1985. hr and Garcia-Coll 1985. Klein et al. 1989. Szatmari et al. 90. Hack et al. 1992. Breslau et al. 1996). In addition. the velopment of these children needs to be evaluated at an age ere learning and attention disorders can be documented all et al. 1995).

The present study examined the long-term neurobehav-

preterm with VLBW. The sample was specifically constructed to evaluate the effects of IVH and hydrocephalus per se on measures of intelligence. neuropsychological functions. academic skills. and behavioral adjustment. Consequently. children were subdivided into preterm groups who demonstrated a history of *progressive* hydrocephalus requiring shunting or *arrested* (compensated) hydrocephalus which did not require shunting. In addition. comparison groups of children born preterm with VLBW and no hydrocephalus were included to control for effects of prematurity. along with a term comparison group. It was hypothesized that neurobehavioral performance would vary with severity of IVH and hydrocephalus. Preterm children who required shunting for progressive hydrocephalus were expected to show the poorest performance in all domains. Children with IVH and arrested hydrocephalus were also expected to show poorer performance relative to non-hydrocephalic preterm children. who in turn would show poorer performance relative to the term group. It was also hypothesized that performance involving motor and perceptual skills would be more likely to show the hypothesized severity effects. This hypothesis was developed because hydrocephalus has initial and primary effects on cerebral white matter. which has stronger relationships with motor and perceptual types of skills (Fletcher et al. 1992a).

Method

SUBJECTS

The 88 children for this investigation averaged approximately 8.5 years of age (range 6 to 13 years) and were born from 1978–88. They were divided into four groups: preterm no hydrocephalus (N=29): preterm arrested hydrocephalus (N=19): preterm shunted hydrocephalus (N=17): and term children (N=23). The children were recruited as part of a larger study of children with different etiologies of hydrocephalus designed specifically to isolate the effects of hydrocephalus on neurobehavioral development (Fletcher et al. 1992a. b: 1995). For the larger study. children were required to have either a Verbal IQ (VIQ) or Performance IQ (PIQ) above 69 on the Wechsler Intelligence Scales for Children–Revised (WISC–R) (Wechsler 1974) or the McCarthy Scales of Children's Abilities (McCarthy 1972) to avoid general effects of mental deficiency. This resulted in exclusion of five children with a history of prematurity. To ensure that children could complete the neurobehavioral tasks and to avoid the possibility of other sources of brain injury and morbidity not related to hydrocephalus and its treatment. children were excluded from the larger study if they had a history of severe psychiatric disorder (autism. psychosis). uncontrolled seizure disorder. other neurological disorder (e.g. head trauma. tumor). child abuse. or if they were unable to speak English. Precise numbers of cases not recruited because of these latter issues cannot be provided since exclusions based on initial contact were not systematically recorded.

For the present study. children were also excluded for complications of prematurity that would obscure effects of hydrocephalus and IVH. including neurological anomalies (e.g. periventricular leukomalacia in the absence of IVH. N=9). Children with severe retrolental fibroplasia resulting in blindness or uncorrectable vision loss (N=1). or severe cerebral palsy represented by inability to use both hands (N=3). were excluded because they could not perform many of the psychometric tests. No child was included who experienced severe bronchopulmonary dysplasia (BPD) (one child excluded, others not recruited because of this problem). This was defined as the presence of cystic changes on chest radiographs where the child was identified with severe BPD, or where BPD was a primary treatment concern resulting in mechanical ventilation or hospitalization >90 days. Some children in the preterm groups had a history of mild to moderate BPD (see Table I), the incidence of which was similar across the preterm groups, χ^2 (2, N=64) <1, P<0.7. In addition, the three preterm groups did not differ on a variety of oxygen support variables (see Table I). All preterm infants had some degree of respiratory abnormality requiring oxygen support and 86% required mechanical ventilation. However, the three preterm groups did not differ significantly in the number of days of mechanical ventilation, F(3,39)<1, or total days of oxygen support, F(3,41)<1. Children with birthweights below 900g were not included to avoid the confounding effects of extremely low birthweight.

All children with a history of prematurity had birthweights <1750 g (mean 1326±222 g) and were no more than 34 weeks' gestation. The data presented in Table I demonstrate that the three preterm groups did not differ significantly in birthweight or gestational age. However, there was a clear trend for longer periods of hospitalization in children with arrested or shunted hydrocephalus. Other complications of prematurity requiring treatment, including hypoglycemia and/or hypocalcemia (about 20% of all groups), jaundice (about 70% of all three groups), infection (about 15% of all three groups), and nutrition problems requiring intravenous hyperalimentation (about 30% of all three groups), did not differentiate the groups. A small number of subjects in each preterm group had a history of, or were under treatment for seizures.

Each child received ultrasonography and/or CT scan in the hospital to evaluate possible IVH. All children were scanned during the first week of life. The severity of IVH was graded using the Papile et al. (1978) system. In the preterm no hydrocephalus group, two children had grade I IVH and seven children had grade II IVH, but no evidence of progressive ventricular dilation. Children in the preterm arrested hydrocephalus group had a history of grade III (N=14) and IV (N=5) IVH which resulted in progressive ventricular dilation apparent on a third-week ultrasound and/or CT scan. Each of these children was treated for ventricular dilation, primarily with medication (e.g. diuretics) and occasionally with lumbar puncture, until ventricular size stabilized. The age at which

Table I: Birth history and medical variables by group

Variable	*Term (N=23)*	*Preterm no hydrocephalus (N=29)*	*Preterm arrested hydrocephalus (N=19)*	*Preterm shunted hydrocephalus (N=17)*
Birthweight (g),				
Mean (SD)	3351 (682)	1338 (205)	1343 (232)	1285 (247)
Gestational age (wk)				
Mean (SD)	39.7 (1.8)	30.1 (1.8)	29.7 (1.8)	29.4 (3.0)
Length of hospitalization				
Mean (SD)	3.65 (2.6)	46.1 (19.7)	67.8 (40.0)	66.9 (31.2)
Mechanical ventilation (%)	–	72	100	94
Days on mechanical ventilation				
Mean (SD)	–	11.6 (17.8)	22.2 (26.9)	20.2 (23.6)
Total days oxygen support				
Mean (SD)	–	22.5 (52.7)	35.9 (45.5)	31.4 (26.6)
Bronchopulmonary dysplasia (%)	–	21	21	31
Jaundice (%)	–	75	84	69
Metabolic problems (%)	–	22	28	19
Infection (%)	–	18	16	06
Necrotizing enterocolitis (%)	–	04	11	06
Nutrition problems (%)	–	19	56	33
Seizures (%)				
None	100	93	84	71
In past, not under treatment	0	7	11	18
Under treatment	0	0	5	12

ilization occurred was not consistently recorded and cannot eliably reported. However, it was possible in these children ontrol ventricular dilation and shunting was not necessary. ventricular system did not necessarily normalize, but the tricular expansion was arrested. The preterm shunted lrocephalus group had grade III (N=9) and IV (N=8) IVH ich developed into severe, progressive hydrocephalus, essitating a shunt in the right hemisphere. On follow-up, shunt remained in the right hemisphere in 15 cases and was oth hemispheres in two cases. All but two children had erienced two to five shunt revisions, with one child experiing one revision and one child experiencing more than five.

RUITMENT OF SAMPLE

st preterm children were identified from the Turner onatal Intensive Care Unit (NICU) at Hermann Children's spital in Houston based on the cohort followed by Landry l. (1984). To increase the sample size, additional children o had been born at the NICU at Texas Children's Hospital in uston were included. Others were recruited through liaison h the local Parents of Premature organization and the yer Developmental Center. Most of these children were born Texas Children's Hospital, with a few children born outside Houston whose parents subsequently moved into the area. e term group represented volunteers recruited for the par- study of children with multiple etiologies of hydrohalus. The preterm children were not strictly a volunteer ple. Rather, charts of previously evaluated children in fol--up studies by Williamson et al. (1982) and Landry et al. 84, 1988, 1993) were reviewed. Potential candidates eived a letter and a follow-up telephone call asking about ir interest in the study.

hildren with shunted hydrocephalus are rare and considble effort was required to recruit and evaluate the 17 chiln in this group. Approximately 50% of preterm children h shunts did not meet one or more of the exclusionary crite- while about 25% of potential cases could not be located, or ised. Thus, the 17 children represent about 25% of the entially available cases. The goal in the case of the other term groups was to recruit subjects using the same procedures as those used for the shunted group. The critical issue is the comparability of the groups on sociodemographic and birth variables, with Tables I and II showing good comparability on these variables. Selection bias is possible, particularly since African-American families were less likely to be located and more likely to refuse to participate. However, there is no evidence that any effects of selection bias differentiate the preterm groups.

As summarized in Table II, the four groups were not significantly different in age, $F(3,83)=1.15$, $P<0.4$; sex, $\chi^2(3, N=88) <1$, $P<0.95$; race, $\chi^2(9, N=88)=6.01$, $P<0.9$; or socioeconomic status based on the Hollingshead–Redlich two-factor scale (Hollingshead and Redlich 1958), $\chi^2(6, N=88)=1.27$, $P<0.98$. Hence, these groups were comparable on a variety of sociodemographic and neonatal history and treatment variables, permitting an opportunity to identify the specific effects of IVH and hydrocephalus on long-term neurobehavioral development.

PROCEDURES

The study was fully approved by the Committee for the Protection of Human Subjects at the University of Texas Houston Health Science Center. Separate consents were obtained for the neurobehavioral evaluations and the MRI.

Each child received a neurobehavioral evaluation in the following areas: intelligence (WISC-R VIQ and PIQ); fine motor skills (speed of finger tapping; peg placement on Grooved Pegboard and Purdue Pegboard, Knights and Moule 1986); visual-spatial skills, including a motor-based copying task (Beery Test of Visual-Motor Integration [VMI]) (Beery 1982) and motor-free matching task (Judgement of Line Orientation [Benton et al. 1994]); language, including measures of phonological awareness (Auditory Analysis Test [Rosner and Simon 1971]), rapid automatized naming (Denckla and Rudel 1974), verbal fluency (Controlled Word Association [Gaddes and Crockett 1975]), and receptive vocabulary (Peabody Picture Vocabulary Test–Revised [Dunn and Dunn 1980]); memory, including serial learning for verbal and non-verbal material using selective reminding procedures (Fletcher 1985) and visual recognition memory (Hannay et al. 1979); and academic skills, including measures of reading decoding, reading

Table II: Sociodemographic characteristics of the sample by group

Variable	*Term (N=23)*	*Preterm no hydrocephalus (N=29)*	*Preterm arrested hydrocephalus (N=19)*	*Preterm shunted hydrocephalus (N=17)*
Age (mo)				
Mean (SD)	106.0 (25.2)	96.5 (24.9)	108.4 (32.0)	97.4 (21.3)
Sex (% female)	48	41	47	41
Ethnic group (%)				
White	74	69	79	77
African-American	5	17	11	17
Hispanic	17	10	11	6
Other	5	3	0	0
Socioeconomic status*				
High (I–II)	39	38	42	30
Middle (III)	22	27	26	35
Low (IV–V)	39	35	32	35

* Based on the Hollingshead–Redlich two-factor scale (Hollingshead and Redlich 1958).

mprehension, and arithmetic from the Woodcock-Johnson sychoeducational Test Battery Revised (Woodcock and ohnson 1989), spelling and arithmetic from the Wide Range chievement Test-Revised (WRAT-R [Jastak and Wilkinson 984]), and sentence writing (Gaddes and Crockett 1975). ehavioral adjustment was measured by two rating scales, the hild Behavior Checklist (CBCL) (Achenbach 1991) and the ersonality Inventory for Children-Revised (Lachar 1982). daptive behavior was evaluated using the Vineland Adaptive ehavior Scales (Sparrow et al. 1984). Finally, a variety of amily measures were obtained, including measures of cohe- ion, communication, and adaptation (Family Environment cale [Moos and Moos 1986]) and material family and psycho- ogical resources (Henderson Environmental Learning rocess Scales [Henderson et al. 1972]; Family Resource Scale Dunst and Leet 1987]). The evaluation required about 5 hours nd was completed in one day with frequent breaks.

The MRI was obtained on all children whose parents consented at the time of the neurobehavioral follow-up: preterm (18 of 19), preterm shunted hydrocephalus (16 of 17), and the term group (20 of 23). Group placement was supported in all cases by previous imaging studies. Sedation using 50 to 75mg/kg of oral chloral hydrate was used in a few cases because of anxiety or restlessness, but was restricted to children with a history of abnormal neuroimaging studies because of the absence of benefit to children with no history of IVH or hydrocephalus.

The MRI scans were read and coded by a radiologist (LAK) and a pediatric neurologist experienced in imaging studies (TPB). The scans were performed on a 1.5-T superconducting magnet (General Electric, Milwaukee, WI, USA) with a protocol consisting of one sequence of sagittal and two sequences of axial images of the brain. The T_1-weighted, sagittal images were obtained by means of a spin-echo two-dimensional sequence with an echo time of 20ms and a pulse repetition time of 700ms. Conventional spin-echo proton density and T_2-weighted axial images were obtained using 30 and 80ms echo times respectively and a repetition time of 2000 to 3000ms. For the T_1 sagittal, proton density, and T_2 axial sequences, the slices were 5mm thick and had a 2.5mm interslice spacing. The T_1 axial slices were 3mm thick and had a 1.0mm interslice spacing.

On the day of the MRI, each child had a conventional neurological examination (Swaiman 1994). This examination consisted of a cranial nerve examination, screening of gross motor and cerebellar functions, deep tendon and other reflexes, skeletal, muscle, sensory, and gait testing. It did not include testing for paraclassical or 'soft' signs.

Table III: Frequencies of abnormalities on MRI obtained at school age in preterm children with a history of arrested and shunted hydrocephalus

Abnormality	*Arrested hydrocephalus (N=18)*	*Shunted hydrocephalus (N=16)*
Lateral ventricle		
Normal	5	2
Small	0	2
Enlarged	13	12
Occipital horn		
Normal	7	3
Enlarged	11	13
Fourth ventricle		
Normal	14	8
Small	0	1
Enlarged	4	7
Third ventricle		
Normal	10	14
Enlarged	8	2
Periventricular leukomalacia		
Mild	3	2
Moderate	3	6
Severe	1	1
Porencephalic cyst	2	4
Corpus callosum		
Hypoplastic	9	15
Partial agenesis	0	1
Abnormal cerebellum	2	8
Atrophy		
Mild	7	7
Moderate	0	8
Severe	0	1
Dysplasia		
Mild	4	6
Moderate	0	8
Severe	0	2

Age range at examination 6 to 13 years (average approx 8.5 years).

STATISTICAL ANALYSIS

The neurological and MRI data were analyzed by computing the percentage of abnormal findings for frequency-based statistical analysis (χ^2). The neurobehavioral data were analyzed with a multivariate approach to repeated measures ANOVA (O'Brien and Kaiser 1985) with one between-subjects factor (group, 4 levels), and one within-subjects factor (task). Significant group × task interactions were followed by univariate ANOVA examining each variable separately. Since task effects were not central to the hypotheses under investigation, they will not be reported. Planned follow-up contrasts were performed, comparing: (a) term versus preterm no hydrocephalus group, (b) preterm no hydrocephalus versus preterm unshunted hydrocephalus, and (c) preterm unshunted hydrocephalus versus preterm shunted hydrocephalus. This allowed tests for the effects of prematurity (a), arrested hydrocephalus (b), and shunted hydrocephalus (c). Bonferroni adjustment of alpha was used to control for type I error at $\alpha \leq 0.05$, so that contrasts had to be significant at $P<0.05/3=0.0167$. All psychometric variables were age-adjusted (mean 100±15) based on either national or local norms. The behavior rating scales are reported as T-scores (mean 50±10).

Results

MRI RESULTS

Table III summarizes the results of the MRI review for the children with arrested and shunted hydrocephalus. The MRI scans were normal in all term children and in all children with prematurity and no hydrocephalus. In the preterm arrested hydrocephalus group, 16 of 18 scans had abnormalities. consisting primarily of enlargement of the ventricular system ($N=13$). In addition to these 13 children. one child had no ventricular abnormalities but did have moderate bilateral periventricular leukomalacia. one child had mild cerebral atrophy. and one child had a Chiari I malformation presumably unrelated to prematurity. Corpus callosum abnormalities ($N=9$. mostly hypoplasia) and periventricular leukomalacia ($N=7$) were common in this group.

The MRI scans of the children in the preterm shunted hydrocephalus group showed the expected changes in the ventricular system. corpus callosum. and other structures consistent with the history of shunted hydrocephalus (Table III). Nine children had periventricular leukomalacia. and all had cerebral atrophy and dysplasia of the cortex that ranged in severity.

NEUROLOGICAL EXAMINATIONS

The neurological examinations were normal in all term and preterm no hydrocephalus children. Some children in the preterm arrested hydrocephalus and preterm shunted hydrocephalus groups had abnormal examinations which revealed spasticity. Two children with arrested hydrocephalus had spastic hemiparesis and in one child this was superimposed on mild spastic quadriparesis. Ten children in the shunted hydrocephalus group had abnormal examinations. including two non-ambulatory children and one ambulatory child with spasic quadriparesis. three with spastic diplegia. and four with pastic hemiparesis.

NEUROBEHAVIORAL DEVELOPMENT

Intelligence

Five children were not administered the WISC-R. For these children. the Verbal and Perceptual-Performance scores from the McCarthy Scales of Children's Abilities (McCarthy 1972) were substituted. The multivariate approach to repeated measures ANOVA for the VIQ and PIQ scores of the WISC-R (or McCarthy) revealed a significant group × task interaction. $F(3.84)=10.15$. $P<0.0001$. As Figure 1 shows. follow-up contrasts for both VIQ and PIQ were significant ($P<0.0167$) only for comparison of the preterm arrested versus shunted hydrocephalus groups. The interaction effect emerged because PIQ scores were significantly lower than VIQ scores in the preterm shunted hydrocephalus group (see Figure 1). This group had lower VIQ and PIQ scores relative to the other three groups. whose scores are similar and clearly in the average range.

Neuropsychological functions

The results for the neuropsychological tests are presented in Table IV (Fine motor and Visual–spatial–motor) and Table V (Language and Memory). The MANOVA was significant in each of the four domains. each of which showed only a significant effect of group: Fine motor. $F(18.160)=2.92$. $P<0.0001$: Visual–spatial–motor. $F(6.164)=8.92$. $P<0.0001$: Language. $F(12.243)=3.18$. $P<0.003$: Memory. Selective reminding $F(6.162)=5.88$. $P<0.0001$. and Continuous recognition Memory. $F(6.168)=3.21$. $P<0.006$. Within each domain. the contrast of the arrested versus shunted hydrocephalus group was significant and in the expected direction (arrested >

Table IV: Means and SDs for Fine motor and Visual–spatial–motor tests (mean 100±15) by group

	Term Mean (SD)	*Preterm no hydrocephalus Mean (SD)*	*Preterm arrested hydrocephalus Mean (SD)*	*Preterm shunted hydrocephalus Mean (SD)*
Fine motor[c]				
N	23	28	17	11
Finger tapping				
D	100.4 (28.4)	101.0 (24.1)	94.9 (24.3)	87.9 (24.8)
ND	106.2 (25.0)	96.3 (22.0)	96.5 (26.1)	86.3 (37.4)
Grooved pegboard				
D	109.1 (10.4)	107.9 (10.1)	96.6 (17.3)	68.6 (38.7)
ND	105.2 (14.9)	102.6 (12.1)	95.3 (15.5)	67.5 (39.0)
Purdue pegboard				
D	95.4 (13.0)	88.9 (16.8)	87.1 (18.8)	57.8 (22.1)
ND	95.6 (10.7)	86.8 (17.0)	90.9 (16.2)	61.1 (21.1)
Visual–spatial–motor[a,c]				
N	23	29	19	15
Berry VMI	93.9 11.5	89.0 11.8	82.6 15.1	69.3 9.4
Judgement of line orientation	100.0 15.0	93.5 15.2	93.1 14.6	70.8 6.8

The group × task interaction was not significant. so contrasts are not reported for individual tests. Significant contrasts are marked by a letter. Absence of a letter (a. b. c [see text]) in the body of the table indicates that the hypothesized contrast was not significant.

[a] Full-term vs preterm no hydrocephalus. $P<0.0167$.

[b] No hydrocephalus vs arrested hydrocephalus. $P<0.0167$.

[c] Arrested vs shunted hydrocephalus. $P<0.0167$.

VMI = Visual–motor integration: D = Dominant: ND = Non-dominant.

groups was significant only in the visual spatial motor domain (term > no hydrocephalus), while comparison of the arrested hydrocephalus and no hydrocephalus groups was significant only in the memory domain for the selective reminding test (no hydrocephalus > arrested hydrocephalus). Inspection of Tables IV and V shows that the shunted hydrocephalus group had dramatically lower scores on every psychometric test.

Academic skills

Table VI summarizes the results of the MANOVA for the measures of academic skills. Again, the group effect was significant for domains involving Reading, $F(6,158)=4.28$, $P<0.0005$, Arithmetic, $F(6,144)=3.65$, $P<0.003$, Writing, $F(3,73)=5.80$, $P<0.002$, and Spelling, $F(4,74)=3.26$, $P<0.03$. In each domain, only the contrast of the shunted and arrested cases was significant, with Table VI showing uniformly poorer scores in all domains in the shunted hydrocephalus group.

Behavioral adjustment and adaptive behavior

Table VII provides a summary of significant findings in the behavioral domain. The group × scale MANOVAs for the Internalizing and Externalizing scales of the CBCL, Family Environment Scale, Henderson Environmental Process Scale, and Family Resource Scale were not significant, $F<1$. In contrast, an ANOVA for the Social Competence Scale (where higher elevations indicate better capacity) was significant, $F(3,79)=6.59$, $P<0.0005$. The contrast of the preterm arrested versus shunted hydrocephalus groups was significant and in the expected direction (arrested > shunted).

Multivariate analysis of the four broad-band factor scales identified a significant group × Scale interaction, $F(9,216)=2.67$, $P<0.007$. Subsequent univariate analysis was only significant for one of these scales, Factor IV/Cognitive Development, with only the comparison of arrested and shunted groups achieving statistical significance, showing greater parental concern about cognitive functions in the shunted group. Tabulation of

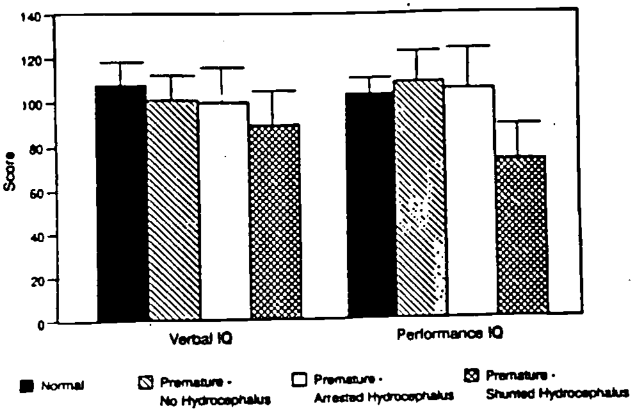

Figure 1: *VIQ and PIQ on the WISC-R (N=83) and McCarthy Scales of Children's Abilities (N=5) mean scores by group. The results show a significant group × scale interaction because preterm children with shunted hydrocephalus have lower PIQ than VIQ scores. Both VIQ and PIQ scores are also significantly lower in preterm children with shunted hydrocephalus.*

Table V: Means and SDs for Language and Memory tests (mean 100±15) by group

Test	*Term Mean (SD)*	*Preterm no hydrocephalus Mean (SD)*	*Preterm arrested hydrocephalus Mean (SD)*	*Preterm shunted hydrocephalus^{d} Mean (SD)*
N	23	29	19	15
Language^{ce}				
Auditory analysis	103.5 (16.6)	90.6 (19.7)	93.9 (16.6)	79.1 (14.8)
Rapid naming	103.3 (12.0)	99.7 (13.1)	101.1 (16.1)	87.4 (27.1)
Verbal fluency	96.2 (16.1)	105.1 (21.2)	102.8 (24.6)	85.2 (10.4)
Peabody Picture Vocabulary–Revised	98.0 (10.8)	99.00 (13.5)	95.3 (14.6)	80.1 (14.5)
Memory				
Selective reminding				
Verbal CLTR^{bc}	98.3 (17.1)	90.9 (20.7)	87.1 (18.3)	69.6 (18.5)
Non-verbal CLTR^{bc}	102.4 (19.3)	96.9 (19.3)	82.7 (21.7)	69.9 (9.7)
Continuous Recognition Memory^{c}				
Hits	100.3 (20.4)	93.2 (21.2)	91.9 (14.7)	70.8 (30.5)
False alarms	85.7 (26.6)	79.6 (26.6)	77.3 (27.3)	68.7 (25.7)

Absence of a letter (a, b, c [see text]) in the body of the table indicates that the hypothesized contrast was not significant.
a Full-term vs preterm no hydrocephalus, $P<0.0167$.
b No hydrocephalus vs arrested hydrocephalus, $P<0.0167$.
c Arrested vs shunted hydrocephalus, $P<0.0167$.
d $N=17$ for Continuous Recognition Memory.
e Group × task interaction not significant.
f Group × task interaction significant, so contrasts marked for individual tests.
CLTR = Continuous Long-term Retrieval.

range (see Table VII) demonstrated pervasive occurrence in the shunted sample (87%), moderate frequency in the arrested sample (31%) and minimal occurrence in the preterm no hydrocephalus (12%) and term (10%) comparison groups. $\chi^2 3$ (N=76)=30.46, P<0.001.

The ANOVA for the composite score for the Vineland Adaptive Behavior Scales yielded a significant group effect, $F(3,83)$=13.05, P<0.0001 (Table VII). The term versus preterm no hydrocephalus contrast and the arrested versus shunted hydrocephalus contrasts were significant (term > no hydrocephalus, arrested > shunted). A separate group × scale MANOVA for the Socialization, Communication, and Daily Living scales of the Vineland Scales yielded a significant group × scale interaction, $F(6,166)$=5.63, P<0.0001. For the Communication scale, only the contrast of the arrested versus shunted hydrocephalus groups was significant. For the Daily Living scale, the contrasts of the term versus preterm groups and the two hydrocephalus groups were significant. As Table VII demonstrates, reductions in adaptive behavior scores are apparent consistent with the severity of hydrocephalus. There were no significant contrasts for the Socialization scale.

Frequency of achievement and attention problems

Each case was examined to determine the number of children vho met psychometric criteria for achievement problems Woodcock–Johnson Basic Reading, Reading Comprehension, alculation, <90), and attention problems (CBCL) Attention Problems scale >63). For achievement problems, the frequen-y was as follows: term group (17% - two children with low cores in reading comprehension, one child with decoding roblems only, and one with decoding and arithmetic prob-ms): preterm no hydrocephalus (20% – three children with roblems in reading and arithmetic, one child with problems ı reading, one with arithmetic problems only); preterm rrested hydrocephalus (50% – three children with arith-ıetic problems, three with problems in reading and arith-ıetic, two with problems in decoding and comprehension and ıe with only comprehension impaired): and preterm shunt-l hydrocephalus (87% – nine with problems in reading and ithmetic, three with arithmetic problems, one with only

Problems scale, the frequency was 13% in the term group, 30% in the preterm no hydrocephalus group, 50% in the arrested hydrocephalus group, and 47% in the shunted group.

To summarize, all but one of the preterm children with shunted hydrocephalus had some form of achievement or attention problem. Both preterm groups with hydrocephalus had a higher rate of attention and achievement deficiencies, but the preterm no hydrocephalus group also had a relatively high rate of attention problems compared with the term group.

Discussion

We hypothesized that the effects of IVH and shunted hydrocephalus would represent a severity effect, with larger effects of hydrocephalus on motor and perceptual skills than language skills. For the intellectual and neuropsychological tests, the severity effect emerged in all domains for hypothesized comparisons of preterm children with arrested and shunted hydrocephalus. However, the shunted group did show poorer performance on motor and visual-spatial tests than on language tests. The behavioral and academic assessments revealed the severity effects that more consistently differentiated all four groups.

The group with shunted hydrocephalus is clearly a significantly disabled group and differs from the other two preterm groups on a qualitative and not strictly on a quantitative basis. As with other studies, these results show that severity of hydrocephalus in preterm children has significant effects on development, extending these findings into multiple areas of skill development and into school-age years. The discrepancy between non-verbal and verbal skills' development is consistent with previous studies showing that shunted hydrocephalus – independent of etiology – is associated with greater impairment of non-verbal cognitive skills relative to verbal skills (Dennis et al. 1981, Fletcher et al. 1992b). This discrepancy may reflect the greater loss of cerebral white matter in posterior areas of the brain and the corpus callosum abnormalities characteristic of many of these children (Fletcher et al. 1992a). It is not likely that shunting per se produces this discrepancy, although the initial placement of shunts in the right hemisphere is noteworthy (Grant et al. 1986). A more likely

ıble VI: Means and SDs for academic achievement measures (mean 100±15) by group

	Term		*Preterm no hydrocephalus*		*Preterm arrested hydrocephalus*		*Preterm shunted hydrocephalus*	
	N	*Mean (SD)*	*N*	*Mean (SD)*	*N*	*Mean (SD)*	*N*	*Mean (SD)*
odcock–Johnson								
eading decoding	23	103.4 (13.5)	25	102.9 (15.6)	18	100.7 (14.9)	15	80.9 (13.4)
eading comprehension	23	107.7 (14.7)	25	106.8 (15.9)	18	104.2 (16.1)	15	83.3 (16.6)
lculation	23	107.5 (12.5)	24	102.6 (17.0)	18	97.2 (19.4)	11	81.2 (14.2)
RAT–R								
elling	23	98.2 (15.6)	25	92.9 (14.0)	18	90.1 (17.9)	12	81.1 (14.8)
ithmetic^{c}	23	94.6 (13.1)	25	93.2 (15.6)	18	86.6 (14.7)	11	73.4 (11.1)
ntence writing^{c}	23	95.7 (14.0)	24	90.8 (23.0)	18	85.7 (22.6)	12	65.9 (23.9)

sence of a letter (a, b, c [see text]) in the body of the table indicates that the hypothesized contrast was not significant.
rm vs preterm no hydrocephalus, P<0.0167.
o hydrocephalus vs arrested hydrocephalus, P<0.0167.
rested vs shunted hydrocephalus, P<0.0167.
roup × task interaction not significant.
RAT–R = Wide Range Achievement Test – Revised.

explanation is that the severity of early hydrocephalus, which required shunting, produced changes in the cerebral white matter that contributed to decrements in overall levels of development and discrepancies in certain specific areas of development.

Children with arrested hydrocephalus consistently obtained higher scores on neurobehavioral measures than did children with shunted hydrocephalus. Although the only statistically significant comparison of this group with children born preterm with no hydrocephalus involved lower scores on measures of serial learning and memory, there was a clear trend for children with arrested hydrocephalus to have lower scores on measures of fine motor, perceptual–motor, and spatial skills relative to term children and to preterm children with no hydrocephalus. These results are not surprising since all children in the arrested group experienced significant ventricular dilation in the neonatal period. Follow-up MRI at school age showed residual ventricular dilation as well as other abnormalities (periventricular leukomalacia, hypoplasia of the corpus callosum) that most likely reflect subsequent loss of cerebral white matter. The lower scores on measures of serial learning may reflect the need to sustain attention over learning trials and the higher rate of attention problems reported by parents of children with arrested hydrocephalus versus no hydrocephalus. In addition, the performance in the motor domain is clearly consistent with the compressive effects of hydrocephalus on white matter pathways near the midline associated with motor and perceptual functions. The absence of statistical significance for comparisons of the preterm no hydrocephalus and preterm arrested hydrocephalus groups may reflect possible lack of power due to the conservative nature of the statistical methods and the relatively small sample sizes.

The power issue is also relevant for comparisons of the term and preterm no hydrocephalus groups. In contrast to large epidemiological studies of birth cohorts (Hack et al. 1992, Breslau et al. 1996), we did not observe general effects of prematurity, particularly in comparisons of term children and preterm children with no hydrocephalus. One exception was on the Daily Living Skills domain of the Vineland Scale. This difference may reflect a social effect of prematurity, reflecting decreased parental expectations because of the special nature of the preterm child to many parents. The preterm no hydrocephalus group also performed worse on perceptual–motor tasks. A comparison of psychometric test scores with normative values generally shows average levels of performance in the preterm no hydrocephalus group except for motor-based activities (e.g. writing, fine motor, and perceptual–motor copying). With a larger sample, it is possible that findings in the fine motor domain would have achieved statistical significance for comparisons of preterm children with no hydrocephalus and term children, reflecting the broader effects of prematurity on the motor system. The effect size of the differences would be small since the present study demonstrated excellent power to detect effect sizes in the medium to large range, such as on the Beery VMI.

Combining the three preterm groups would have increased the size of the mean differences relative to term children and additional comparisons of term children versus a combined, more heterogeneous group of preterm children, could have achieved statistical significance. The effect sizes for the differences would be small and would have implied effects of prematurity per se when the differences actually reflected severity and progression of hydrocephalus. The extent to which large-scale birth cohort studies have obtained statistical significance in outcome domains because they have combined cases that vary in neurological complications and outcomes is an important issue. Using IVH as the example, the present study suggests that imaging abnormalities are present in many children who do not have abnormal findings on neurological examination or who have a history of hypoxic–ischemic encephalopathy or related findings. The factors underlying the documentation in epidemiological

Table VII: Means and SDs from behavioral adjustment, family, and adaptive behavior measures by group.

	Term Mean (SD)	*Preterm no hydrocephalus Mean (SD)*	*Preterm arrested hydrocephalus Mean (SD)*	*Preterm shunted hydrocephalus Mean (SD)*
Child Behavior Checklist[d]				
N	22	29	19	17
Social Competence[e]	44.5 (12.1)	45.4 (9.8)	40.8 (8.7)	32.4 (7.3)
Personality Inventory for Children–Revised[d]				
N	20	25	16	15
Factor IV: Cognitive development	52.4 (9.7)	55.8 (14.5)	61.6 (13.7)	84.7 (19.1)
Vineland Adaptive Behavior Scales[f]				
Composite[a,c]	100.6 (16.6)	91.9 (14.2)	91.1 (14.4)	71.6 (12.7)
Communication[c]	100.6 (16.6)	96.5 (14.9)	97.6 (15.0)	77.2 (14.0)
Daily Living[a,c]	103.1 (11.6)	93.4 (13.2)	91.7 (15.1)	66.3 (15.0)
Socialization	97.8 (14.6)	92.2 (11.4)	90.5 (13.2)	86.3 (15.0)

Absence of a letter in the body of the table (a, b, c [see text]) indicates that the hypothesized contrast was not significant.

[a] Term vs preterm no hydrocephalus, P<0.0167.

[b] No hydrocephalus vs arrested hydrocephalus, P<0.0167.

[c] Arrested vs shunted hydrocephalus, P<0.0167.

[d] Mean = 50 ± 10.

[e] Raw score.

[f] Mean 100 ± 15.

neurobehavioral domains, and elevated risks of learning, attention, and behavior disorders, may include the presence of subgroups with various combinations of less obvious neurological abnormality. In this study, the risk of achievement deficiency, attention problems, and behavior problems increased with the presence of hydrocephalus and other neurological sequelae in the present study, but were largely restricted to children with abnormal MRI scans (i.e. arrested and shunted hydrocephalus) that are not ordinarily obtained in epidemiological cohorts. This was the strongest evidence for the pattern of severity effects hypothesized for this study.

Smaller studies are also subject to possible selection bias. This sample is overrepresented by white children for this geographic region. African American families with preterm children were harder to locate for follow-up, more likely to meet exclusionary criteria, and less likely to volunteer for the study. At the same time, the samples were well balanced on sociodemographic and family variables. Although the sample sizes were appropriate for medium to large effect sizes, there was not sufficient power to detect smaller effects in domains where variability was higher, such as the fine motor and spelling domains. The term group did not exclude children who may have had significant problems with academic skills and/or attention. Although such children were not specifically recruited, they were not excluded because these problems have a relatively high prevalence in the general population. Nonetheless, there may have been slight overrepresentation of these children in the term group, particularly for attention problems. The percentages, however, may overstate the frequency of attention problems, since only three of the 23 term children had elevated CBCL Attention Problems scores. No ttempt was made to apply formal categorical diagnostic cri-eria for either achievement or attention problems other than he dimensional definitions employed, which might have yield- d somewhat different results.

Despite these limitations, this study clearly documents ervasive deleterious effects on multiple areas of neurobehav- ral development in children with a history of IVH who equire shunting for the control of hydrocephalus. The chil- ren were significantly handicapped and required intensive ehabilitative and special school services. Fortunately, the revalence and severity of IVH is declining and fewer preterm hildren now receive shunts. The outcomes are not likely due to unt placement per se, but reflect the presence and severity of ydrocephalus in a manner consistent with studies of other iological groups (e.g. spina bifida myelomeningocele) associ- ed with early hydrocephalus. The presence of severe IVH d the need for a shunt should alert the clinician to the tremely high risk for subsequent neurodevelopmental mor- dity. This risk is lower in preterm children who do not require unting, but there is more variability in the long-term neu- behavioral development of such children. The presence of y form of ventricular dilation in the neonatal period increas- the level of risk of the child, particularly in areas involving tention and academic performance.

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Parent Perceptions of an NICU Follow-Up Clinic

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ABSTRACT

Purpose: to learn how parents perceived their experiences during a visit to an academic center's NICU follow-up clinic and what they would change about the clinic if given the opportunity.

Design: a qualitative study utilizing artifact collection, participant observation, and semistructured interviews

Sample: seven families that went to the clinic.

Main outcome variable: what parents did and did not like about the clinic and what they would change about the clinic.

Results: parent concerns included lack of information about the clinic prior to the first appointment, length of wait prior to seeing the physician, preference for more appropriate toys for use during the wait, desire for additional explanations during the exam process, uncertainty about the effects of prematurity on their child's development, and need for more developmental and parenting information.

HE SURVIVAL RATE FOR PREMATURE INFANTS HAS increased dramatically in the past decade; centers report ercent survival in infants weighing 500 through 1,250 gm th.[1] However, very low birth weight (VLBW) premature ts (<1,500 gm) experience a greatly increased incidence arning and behavior prob-[2–4] The rates of disability according to birth weight; ts born weighing less than gm exhibit more neurodepmental problems than nts born weighing between and 1,499 gm. In one study, rates of mental retardation in e two groups were 21 and 8 ent, respectively; of cerebral y, 9 and 6 percent; of severe al disability, 25 and 5 percent; of hearing disabilities, 24 and percent.[3] In addition, 21 pert of VLBW infants exhibit avioral problems, and 25 pert need special-education cement.[4]

Because the consequences of maturity extend beyond the CU course, it is important at premature infants receive systematic monitoring and rly-intervention services.[5] To facilitate early detection of velopmental problems and appropriate referral to early-ervention services, many NICUs have follow-up programs. The purpose of these programs is to perform ongoing evaluations of the growth and development of high-risk and moderate-risk infants discharged from the NICU. NICU follow-up clinics generally do not replace routine pediatric care. Rather, they provide examinations and testing specifically designed to identify medical and developmental problems.

The screening component of our NICU follow-up clinic, located in a large metropolitan city, was experiencing poor compliance with appointments (mean no-show rate 48.5 percent; range 23 to 100 percent). Poor compliance is not, however, uncommon.[6,7] Several researchers have implemented center-based programs to address the issue. These programs included such incentives as diapers, formula, toys, clothing, food;[8] phone calls; reminder letters; and cash payments.[9] Results revealed no significant differences between the control and the experimental group in any of these studies. Therefore, we decided to investigate our follow-up clinic as it existed, to learn how to improve the clinic and how to increase compliance with appointments.

This study had two objectives. The first was to learn what parents did and did not like about the clinic. The second was

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TABLE 1 ■ High-Risk and Moderate-Risk Enrollment Criteria

High-Risk Criteria
Birth weight <1,200 gm
Gestational age ≤30 weeks
Intraventricular hemorrhage ≥Grade II
Ventriculomegaly, porencephaly
Hydrocephalus
Microcephaly
Periventricular leukomalacia
Hypoxic-ischemic encephalopathy
Bronchopulmonary dysplasia
Ventilator dependent ≥1 month
Persistent fetal circulation, paralysis, alkalosis at 1 week
Discharge team discretion
Moderate-Risk Criteria
Birth weight 1,201–1,500 gm
Gestational age 30–32 weeks
Intrauterine growth retardation
Congenital infection
Persistent fetal circulation, ventilator <1 week
Mechanical ventilation >1 week <1 month
Hospitalization >2 months
Documented hypoglycemia
Discharge team discretion

to learn what parents would change about the clinic if given the opportunity to do so.

METHOD

The goal of qualitative research is to make a discovery that leads to new insights.[10] A qualitative method allows firsthand encounters with participants that provide the rich data needed to understand their perspective. This study utilized a qualitative method of inquiry consisting of artifact collection, participant observation, and semistructured interviews.

Site

The site chosen for this study was the screening component of the NICU follow-up clinic at the University of Maryland Hospital in Baltimore. The purpose of the clinic is to evaluate the growth, medical, and developmental status of high-risk and moderate-risk infants who are discharged from the NICU and meet the criteria listed in Table 1. In order to accomplish this, the clinic is divided into two components: screening and evaluation. All infants attending the clinic are seen by a neonatology attending physician or fellow (that is, a pediatrician in a three-year neonatology training program). All infants receive a physical and neurologic exam and the Maryland Premature Developmental Inventory (MPDI).[11] Infants who pass both the neurologic exam and the MPDI return for another screening appointment at the next regularly scheduled age. Infants who fail either one are referred to the developmental team for a full evaluation. The evaluation may occur that day or at the next available appointment. Members of the developmental evaluation team may include a developmental pediatrician, a psychologist, a physical therapist, an occupational therapist, and a speech and language pathologist. On a typical clinic day, 15 children are scheduled for screening appointments with neonatology. The screening component of the clinic is usually staffed by one neonatology attending physician and two neonatology fellows.

The NICU follow-up clinic serves families with diverse characteristics. A slight majority (51.4 percent) come from Baltimore City. Many other families come from suburban and rural areas throughout the state of Maryland. Most families (63.3 percent) are African American; almost all (32.9 percent) of the others are Caucasian. Most families (57 percent) consist of one or more children and a single mother. Mothers are the primary caregivers in 84.3 percent of the families; however, foster parents, grandparents, and aunts also serve as primary caregivers. Mothers range in age from 13 to 40 years; their level of education varies from some junior high school to completion of college. Finally, the clinic serves families of diverse socioeconomic status; incomes vary from $4,999 to $70,000.

Participants

Seven families served as the primary participants in this study. These families were chosen using ideal-case, extreme-case, and reputational-case criterion-based selection procedures.[12] Ideal-case selection procedures were used to identify two families from middle-class backgrounds who consistently attended all clinic appointments. One family was African American and had twins who were 18 months of age; the other family was Caucasian and had a 6-month-old infant. The parents in both families were married, and the children were firstborns. Extreme-case selection procedures were used to select two families with single teenage

thers who were on medical assistance and
ed on public transportation. Both families
re African American. One family had a 6-
nth-old infant, and the other had a 14-
nth-old toddler. One of these families had a
tory of not attending clinic appointments.
ally, reputational-case selection procedures
e used to identify two families being seen
the two neonatologists with the most favor-
reputations: the neonatologist who is the
ic director and the neonatologist who
nds the most time with her patients. The
ents in both families were middle-class and
rried; the infants were both 3 months of
. One family was African American, and the
er was Caucasian. Because all of the babies
uded thus far were firstborns, a family in
ch the premature infant was the third-born
d was also chosen. This family was middle-
s African American, with a single mother
a 24-month-old child. All eight children
e developmentally appropriate for their
sted ages. Grandparents who attended the
c appointments served as active sources of
ort in three of the seven families.

Data Collection

ata collection consisted of one noninterac-
and two interactive methods. The noninter-
e method was artifact collection.[13] The
dance records of the NICU follow-up clinic
reviewed to examine scheduling and atten-
e issues for the year preceding this study
the six-month period during it. The atten-
e records contained a weekly list of families
duled for a follow-up appointment. The
c coordinator coded the list to designate
her the family attended the clinic, called to
edule the appointment, called to cancel the
intment, or failed to keep the appointment
out calling.

he interactive methods used were partici-
observation[12-15] and semistructured inter-
ing.[12,13,16,17] The first author (Hussey-
ner) conducted all observations and inter-
. All seven families were observed during
ICU follow-up clinic visit. The observations
n when the family entered the clinic and
nued while they waited for the physician
hroughout the actual appointment. Using
hand, the author took in-depth notes dur-
he observation. Detailed field notes were
n following the observation.

Within three weeks of each participant observation, a semistructured interview was conducted with six of the families; one family was not interviewed despite many attempts on the part of the researchers to do so. In accordance with parental preferences, three interviews were conducted in the family's home and three by phone. All interviews were tape-recorded; they ranged in length from 30 to 50 minutes. The interviews were subsequently transcribed. During the transcription process, the researcher's comments and reflections were inserted into the text.

Interpretation of Data

Although most of the data analysis occurred after all data were collected, techniques such as memo writing and reflections[18] were used throughout the data collection process to develop thoughts and insights. The researcher used recursive member checks throughout and at the end of interviews to review information gathered with parents to verify that she had understood parents' responses accurately.

Once the data were collected, a process of inductive data analysis began. First, the data were scanned.[12] This involved rereading the data to check for completeness. As researchers scanned the data, they wrote notes in the margins to record their impressions of events, comments, questions, and uncomfortable moments that occurred frequently or that seemed especially important. These notes served as the basis for sorting the data into codes. The codes were transformed into themes according to their patterns and common characteristics, and these themes were further grouped into conceptual categories. The relationships among these categories served as the basis for the working hypotheses that were developed regarding the dynamics of the NICU follow-up clinic.

Following the analysis process, a member check was conducted with each parent. The purpose of the member check was to ensure that the researchers had interpreted the parents' meaning correctly and to clarify and verify themes. All member checks were conducted over the phone and recorded. Following each member check, which lasted approximately 15 minutes, the conversation was transcribed, and comments and reflections were inserted into the text.

FINDINGS

Through inductive data analysis, seven

themes were identified in this study. These themes were scheduling, waiting room, exam room, physician activities, parent concerns, parent likes and dislikes, and suggestions.

Scheduling

During the year preceding the study, 48.5 percent of the families failed to attend their screening appointment. (Either they canceled the appointment, or they missed the appointment without canceling.) During the six months this study was conducted, the noncompliance rate was a little better (40.7 percent), but it was still highly variable. During one appointment, a parent hypothesized that the long wait at the clinic was due to overscheduling. Later, during the interview, she stated: "I know people cancel out. I don't know if there's another way to not do that and keep the appointment on time and keep it flowing." It was speculated that excessive no-shows may have led the clinic coordinator to overschedule appointments. This was confirmed when the coordinator described her scheduling procedures.

One family attended the clinic on a day when the schedule was very light—ten babies were scheduled and only six showed up. As a result, this family waited only 15 minutes to see the physician. This wait was very acceptable to them; they were the only family that did not complain about the wait.

The other six families spent between one hour and 15 minutes and one hour and 50 minutes waiting for the physician. During this time, they worked very hard to keep their children "together." The wait always began in the waiting room and continued in the exam room. The following information relates only to these six families.

Waiting Room

After signing in, families went to the waiting room. Within 10 to 15 minutes, a nurse brought the families (one at a time) to a small room where the child was weighed and measured. After the nurse completed the necessary measurements, she told the family to go back to the waiting room until their name was called. All families participating in the study indicated confusion about whether they should dress their children at this point. During one observation, the mother asked the nurse if the physician would need her child undressed, and the nurse replied that she was not sure. After consulting with another professional, the nurse told the family that the physician would need the child undressed, but that they should dress him so that he would not get cold while he waited. During another observation, one grandmother reported that she always dressed the twins after they were weighed because at a previous visit she had not done so, and they got so cold while they waited that she had to wrap them in blankets. During a third observation, a parent commented: "The clinic should notify parents to bring a blanket because the baby will be waiting undressed." This family wrapped the baby in a hospital sheet to keep her warm while they waited one hour and 20 minutes in an air-conditioned office.

Once the families returned to the waiting room, they waited between five minutes and one hour before they were taken to an exam room. During this time, the parents held their children, guided play, managed behavior, provided snacks, and talked about how long they were waiting. Parents of young infants often asked if there was another place they could wait because they were concerned about having their baby around toddlers. Parents of toddlers preferred the waiting room: "I think it was better in the waiting room, 'cause at least she could play," was how one parent put it.

Exam Room

The nurse took the family to an exam room as soon as one became available. There the clinic coordinator took two pictures of the child—one for the clinic's records and one to be given to the family as a keepsake. The families then waited anywhere from 30 minutes to one hour. Once again, parents held their children, provided snacks, managed behavior, and talked about the wait. In addition, they changed diapers, dealt with boredom, and consoled their crying infants. During one family's wait, a grandmother told the mother: "We should let the doctor come stand with the baby for two hours trying to keep him quiet and happy."

Physician Activities

Each of the four physicians engaged in the same 12 activities. The order of these activities was very similar across physicians. A typical appointment was conducted as follows. The physician began by introducing him- or herself, giving the family a copy of the child's picture, iking them if they had any concerns or ms. After the family responded to this nded question, the physician conducted a interview to obtain information concern- hospitalizations, medications, immuniza- feeding, and sleeping. Next, the physician ed the child's growth chart with the fami- of the families viewed this as important re relieved to find that their children were ıg well. One parent commented: "I like how she's doing on the chart. She was o early; it's nice to see that she's finally ıg up with how she's growing." The ian then conducted a developmental ng to determine if the child was function- a level commensurate with his age and of prematurity. Following this screening, l and neurologic exams were conducted. end of the appointment, results were d, and the parents were told when they return for their next appointment. In ı, parents reported that they were often lobal recommendations. For example, ther said she was told: "Just provide him ts of different toys and lots of different periences." Throughout the appoint- he physician wrote notes on numerous ıd helped to console the baby.

Parent Concerns

ıughout the appointment and during ent interviews, parents voiced many con- out the appointment. These concerns ded into seven issues. The physicians d two of the issues completely, two par- ıd three inadequately. The physicians ely addressed the issue of dressing and ng and the issue of physical growth. The ıe arose again and again for parents. every observation, the physician d it clearly by telling the family how far ss the child and when to dress him. The n also clearly addressed the parents' ıs about their child's growth. On all s, the physician used the child's growth facilitate this discussion.

hysicians partially addressed the issue of ity. When parents asked them questions e effects of prematurity, they answered tions, but they did not answer them nough. Consequently, the parents left with new, unanswered questions. The ıs also partially addressed the issue of the exam process. Parents wanted the physician to provide more explanations during the exam. One mother commented: "Well, I didn't know—that's why I asked questions. 'Why do you listen for that?' 'What are you listening for?' She could be telling me what she was looking for as she was checking him out. So many physicians have checked him over so many times. I guess—I don't know—I more or less trust what they're doing, you know, that it wouldn't hurt him or anything like that. But I do like to know why they're doing it."

The physicians addressed three issues inadequately. All three of these issues had to do with the child's development. All the parents wanted the physician (or other professional) to provide more developmental information. First, they expressed a desire to have parenting issues addressed. One mother of 18-month-old twins stated: "Well, we're trying to potty train them and it's kinda hard. They don't talk about those things, not at all." Second, all the parents said they needed to learn more about developmental milestones. The mother of a 6-month-old infant explained: "She didn't really tell me. I pretty much asked more questions about where he was supposed to be and what he was supposed to be doing more than she told me how he was doing." When asked if she felt her questions were answered, she responded: "Yeah, I do. But I feel that if I didn't ask the questions, they wouldn't have told me. You know. Not that if he's doing okay, but—um—what he's supposed to be doing next. They didn't tell me, but I asked." Finally, parents demonstrated interest in learning specific home activities that they could do to foster their child's development. "If they could give me ideas of activities I could do with him to further his development," a first-time mother said. "Or that would help him to get ahead, or whatever, you know. Because I don't know. I'm really—I'm a new mom, and not exactly sure of all the things I need to be doing or that I could be doing, you know, to help him out."

Parent Likes and Dislikes

When asked about their likes and dislikes, the parents had a lot to share. Regarding their likes, all parents said they felt reassured knowing that their child was all right. One parent's response was typical: "Being reassured that he was on line with his weight, length. That he was on line for how old he was or his gestation date, whatever

/ call it. Just reassurance that he was doing well." In addi- ı, most parents were grateful for the information they ived. One mother stated that she liked "the physicians and / they explain things." Another mother explained that she l "the caring, the gentleness." She elaborated by adding: / mother was really impressed with the physician herself, ı how gentle she was and how she explained everything ıd of time. I couldn't get over how gentle she was. It ıed like she was truly concerned. Usually it's just like 're there and it's my job and I have to see this baby. It ıed like she was really interested."

/hen asked what they liked least about the clinic, all fami- (except the family that waited only 15 minutes due to : scheduling) mentioned the wait. At the end of one intment, a mother indicated that she probably would not n to the clinic because of the wait. During the interview, laborated by saying: "Well, the wait mostly. We are pay- or this, you know. The insurance company and we're .g partially. So—um—I feel he's right on course as far as he's doing. I kind of feel that he's right on line, and re not really doing anything for him. I'm not getting nuch out of it, and I'm waiting a long time." All families l that they did not receive enough developmental infor- ın, nor did they receive any play recommendations. families remarked that they were not given explanations g the exam. In addition, parents talked about the ce of toys in the exam room and the lack of develop- ılly appropriate toys for infants and young toddlers in aiting room. One mother also commented that she dis- ıot knowing what was going to happen at the clinic: "I really have any idea what to expect. I asked the lady on ıone, and she told me they were gonna do tests on her, didn't know what kind of tests they were gonna be. I know what I was getting into. They could have been her needles for all I knew."

Suggestions

parents readily offered suggestions. One parent was ılarly articulate: "You could have someone—if the ian didn't have the time to explain to me what he be doing or what I could be doing to further his pment, you know—[someone] in between our wait ı show me some things to do with him. And maybe we :ven try a few things with him, because we're there. I ee how he would react, or if I would be able to do it ly." When we shared this suggestion with the other ;, they all responded very positively, commenting: "It'd to get some helpful hints and look at things you can ı your child at home to help your child get to that) where they want her to be." And: "I wouldn't mind wait] as much, because we would be doing some- All parents commented that they would like a pam- · handout to supplement the session.

The mother who did not know what was going to happen at the clinic suggested that parents be sent a letter explaining the purpose of the clinic, what would happen, the length of the wait, and what to bring. This parent, along with three other parents, requested that someone periodically come to the exam room and tell them how much longer they had to wait. One grandparent recommended that magazines and coffee be available for the families while they waited. All parents said that they would like toys in the exam room, "something to keep him occupied." In addition, some families suggested that the physician provide more explanations during the appointment.

DISCUSSION

The data obtained from this study illustrate the array of parent responses to a NICU follow-up program. In order to begin the process of improving on parents' areas of concern, the findings of this study were shared with the staff of the NICU follow-up clinic. Staff were not aware that families were experiencing an excessive wait. As a first step to addressing this issue, a protocol for monitoring the flow of families in the clinic was immediately implemented. Staff were also unaware of most of the parents' other concerns. To address these concerns, magazines were placed conveniently throughout the waiting room; the letter describing the clinic to families was clarified to provide them with more specific information; staff began telling parents that they would need to undress their babies for the physician, but that they should put some clothes back on so that the baby would not get cold; and parents were encouraged to bring a toy from the waiting room into the exam room. Furthermore, physicians were encouraged to provide more explanations during their exam.

The staff viewed the suggestion of a developmental session as excellent and felt that it deserved investigation. Not only did the parents request further developmental guidance, but there is support for such a program in the literature. Lott found parental involvement a key to successful developmental intervention, stating that a few well-spent minutes teaching parents about their baby can have greater influence than many hours spent actually caring for the baby.[19] McCain found that parents of high-risk, premature infants need information about developmentally stimulating activities.[20] In a study designed to examine deliberate learning undertaken by mothers of premature or low birth weight infants, the most frequently cited topic of inquiry was infant development.[21] Many researchers support a dual purpose for NICU follow-up clinics: to detect developmental delay and to inform parents about development.[5,19,20] It appears, at this point, that our NICU follow-up clinic meets the first purpose but not the second one.

Since the study, the NICU follow-up clinic staff have begun to implement a parent training component with a

.mple of the families that attend the clinic. This component provided by an infant development specialist. Parent train- g is offered while parents are waiting to see the physician; it overs parenting issues, future development, and home activi- es. The specialist provides toys, so the parents can try the fferent activities and get immediate feedback. A few toys are ft with the family to entertain the child while they wait. The ecialist also offers the families the opportunity to take the ys home on loan. In addition, a developmentally focused imphlet was developed. Parents are given this pamphlet to inforce recommendations at home.

Because some problems of prematurity extend beyond the ICU course, it is important that these infants receive sys- matic monitoring and early-intervention services as eded.[5] To facilitate early detection and referral, NICU fol- w-up clinics must attract and keep parents in their pro- ams. As noted, many of the problems in our clinic were not parent to the clinic staff and were easily addressed once ey were identified. This qualitative study uncovered several rent concerns, identified possible solutions to the problems, d encouraged the implementation of changes.

Implications for other programs are twofold. First, other ograms, if they are not already doing so, may want to con- ler incorporating suggestions offered by parents in this idy: minimize wait time, clearly explain the clinic visit to rents, and inform parents about development. Second, CU follow-up clinics may benefit from the use of a qualita- e investigation of their program to determine needed areas change unique to their families and their setting.

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A Longitudinal Study of Developmental Outcome of Infants With Bronchopulmonary Dysplasia and Very Low Birth Weight

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ABSTRACT. *Objective.* Bronchopulmonary dysplasia (BPD) is now the leading cause of lung disease in US infants. In a large regional cohort, we tested the hypothesis that despite innovations in neonatal care, very low birth weight (VLBW) infants (<1500 g) with BPD had poorer developmental outcomes than nonaffected infants during the first 3 years of life, and that BPD predicted poorer outcome beyond the effects of other risk factors.

Methods. Three groups of infants (122 with BPD, 84 VLBW without BPD, and 123 full-term) were followed longitudinally to 3 years of age with the Bayley Scales of Mental and Motor Development. Comparison groups of VLBW infants without BPD and full-term infants did not differ in sex, race, or socioeconomic status. Statistical analyses included hierarchical and stepwise multiple regression.

Results. Infants with BPD performed more poorly at all ages. By 3 years, cognitive and/or motor development was in the range of retardation (<70 standard score) for 21% to 22% of infants with BPD. In multiple regression analyses controlling for socioeconomic and neonatal risk conditions, BPD had an independent negative effect on motor outcome at 3 years. Neurologic risk, a summary measure of neurologic problems other than intraventricular hemorrhage, and the presence of BPD independently predicted motor delay. By 3 years, social class, race, and neurologic risk predicted mental outcome, suggesting that the specific effects of BPD are primarily on the motor domain.

Conclusions. In VLBW infants, BPD predicts poorer motor outcome at 3 years, after control for other risks. Cohorts of infants with BPD also had higher rates of mental retardation, associated with greater neurologic and social risk. These findings underscore the need for intensive prevention and habilitation efforts for this growing group of VLBW survivors, as well as investigation into the potential role of BPD in the higher rates of learning disabilities in VLBW cohorts at school age.

Pediatrics 1997;100:987–993; *bronchopulmonary dysplasia, very low birth weight, infant development, chronic lung disease, surfactant, socioeconomic status.*

ABBREVIATIONS. BPD, bronchopulmonary dysplasia; VLBW, very low birth weight; SES, socioeconomic status; NICU, neonatal intensive care unit; ROP, retinopathy of prematurity; MDI, Mental Development Index; PDI, Psychomotor Development Index.

Improved survival rates for smaller, sicker, very low birth weight (VLBW) infants related to advances in neonatal intensive care have resulted in a corollary increase in incidence of bronchopulmonary dysplasia (BPD).[1] BPD, virtually unknown a generation ago, is now the third leading cause of chronic lung disease in children, and the leading cause of lung disease in infants in the United States,[2,3] with >7000 infants diagnosed yearly.

BPD is the term used to describe the clinical, radiographic, and pathologic sequelae of prolonged mechanical ventilation occurring in the lungs of some newborn infants.[1] BPD most often occurs in ventilated preterm infants and is inversely related to gestational age.[4] Pulmonary immaturity, oxygen toxicity, and barotrauma are paramount in the etiology of BPD.[4,5]

Previous studies addressing developmental outcome for infants with BPD have been inconsistent in their findings, with many reporting poorer growth and developmental outcomes and greater evidence of neurologic problems, particularly cerebral palsy.[5–10] Sample sizes of most studies are small, (generally <30), and BPD has been variously defined and confounded with other medical conditions known to relate to poor outcome, ie, intraventricular hemorrhage, periventricular leukomalacia, and lower gestational age.[9,12,13] Impact of social class and racial parameters on outcome has also been rarely assessed,[12] leading to debate about whether the negative sequelae of BPD are secondary to associated deleterious medical or social conditions or independent effects. Most studies were completed before routine use of cranial ultrasound evaluations in neonatal nurseries. Information was not available regarding the contribution of intraventricular hemorrhage and periventricular leukomalacia to developmental delays.[6,12] Some studies averaged mental and motor outcome scores[7] or used scores uncorrected for prematurity,[9] making interpretation of findings problematic. In addition, there is little information describing the development of infants with BPD after the introduction of exogenous surfactant therapy, which was expected to improve pulmonary and developmental outcomes in premature infants

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surfactant and postnatal steroid use had become standard practice. Despite these innovations, BPD infants were hypothesized to perform more poorly on developmental assessments to 3 years of age compared with VLBW infants without BPD and with full-term infants of similar age, race, gender, and socioeconomic status (SES).

SUBJECTS

All infants with VLBW and BPD admitted to the neonatal intensive care units (NICU) of hospitals in the Cleveland region were eligible for the study, and were prospectively, consecutively recruited. For the approximately four-county region, all infants with BPD were cared for in the NICU of the three participating hospitals, which had the only level 3 NICU facilities in the region, providing an exhaustive regional sample. Infants with BPD were preterm, <1500 g at birth, requiring supplementary oxygen for >28 days, with radiographic evidence of chronic lung disease.[4] A partial stratification sampling strategy was adopted to enroll adequate numbers of subjects without socioeconomic disadvantage or severe neurologic risk so that these factors could be investigated in data analyses. Infants diagnosed with BPD who were free of neurologic problems other than grades I and II intraventricular hemorrhage and who were not socially disadvantaged (ie, Hollingshead classification IV and V)[16] were exhaustively recruited. The remainder was recruited randomly by approaching the family of the next available BPD diagnosed-infant who could be accommodated in the follow-up schedule. Parents of infants with BPD were approached by a research assistant in the NICU as soon as possible after the diagnosis of BPD was made by the attending physician.

For each infant with BPD, the next-born VLBW comparison infant without BPD of the same race and SES born during the same period was recruited. Term infants were recruited from the newborn nurseries. Information about the study and return addressed postcards were provided to all mothers in the nurseries. For each infant with BPD enrolled, the next term infant equivalent in race and SES with a returned postcard indicating parental willingness to participate was recruited, if eligibility criteria were met. Infants with major congenital malformations or drug exposure or whose mothers had major psychiatric or physical illness, human immunodeficiency virus, or mental retardation, or who lived >2 hours driving distance were excluded. VLBW infants without BPD were preterm, of <1500 g birth weight, and required oxygen supplementation for <14 days. Term infants had no diagnosed medical illnesses or abnormalities at birth and were >36 weeks' gestational age and >2500 g birth weight for singleton infants.

During the recruitment period (1989 to 1991), 250 infants with BPD were identified, of whom 89 were excluded (35 for drug/alcohol exposure, 21 for all other exclusions, and 33 who could not be accommodated into the testing schedule, all of whom were by definition of lower SES, being on public assistance), leaving 161 eligible VLBW infants with BPD. Twenty (12%) refused the study, 14 (9%) died, and 5 (3%) were unable to be contacted. Of 122 infants enrolled, 7 died, 1 withdrew before 8 months of age, and 4 were lost to follow-up, leaving 110 (96% of survivors) infants with at least one follow-up visit. Of these, 97 (88%) were seen at 8 months, 91 (83%) at 12 months, 94 (86%) at 2 years, and 98 (89%) at 3 years.

Of 214 VLBW infants without BPD, 24 were excluded for drug/alcohol exposure, 34 for oxygen supplementation for 21 to 28 days, and 46 for all other exclusions, leaving 110 eligible VLBW infants without BPD, of whom 8 (7%) were unable to be contacted and 18 (16%) refused the study. Of 84 recruited, 2 withdrew, and 1 was lost. One infant died at 2 years of age. Of 81 (96%) with a follow-up visit, 52 (64%) were seen at 8 months, 59 (73%) at 12 months, 70 (88%) at 2 years, and 70 (80%) at 3 years. Of 123 term infants, 6 withdrew and 5 were lost. Of 112 (91%) seen for follow-up, 97 (87%) were seen at 8 months, 101 (90%) at 12 months, 99 (88%) at 2 years, and 95 (85%) at 3 years.

from the hospital chart or maternal interview included the following: infant gestational age based on a combination of Ballard[17] examination and dates from the last menstrual period, birth weight (in grams), length and head circumference (in centimeters), Apgar scores at 1 and 5 minutes, and the presence/absence of respiratory distress syndrome and BPD. Noted were the presence/absence of patent ductus arteriosus, necrotizing enterocolitis (proven with or without surgery), retinopathy of prematurity (ROP), abnormal hearing test results, number of days that ventilator support was required, number of days that supplemental oxygen was used, peak bilirubin levels, and septicemia. Presence/absence of the following neurologic abnormalities was noted: minor neurologic malformations, seizures, echodense lesions, porencephaly, hydrocephalus, ventriculoperitoneal shunt, meningitis, and periventricular leukomalacia. A summary variable (the neurologic risk score) using 0 for absence and 1 for presence of any of the above neurologic risk factors was calculated. The neurologic risk score ranged from 0 to 8.

Cranial ultrasound studies were obtained prospectively for all VLBW infants during their hospital stay. Protocols for ultrasound studies were similar across the three NICU facilities from which infants were recruited. For two sites, protocols were identical, with all infants screened at 3, 10, and 30 days after birth. At the third site, all infants were screened at 7 days, with follow-up clinically determined. Thus, all infants were screened prospectively within the first week of life. For intraventricular hemorrhage, a rating of severity based on extent of lesion was devised; no hemorrhage on ultrasonography was scored as 0, and lesions were graded from 1 to 4 based on the criteria of Papile.[18] Ratings were based on the most severe lesion diagnosed. For the present study, intraventricular hemorrhage was evaluated separately from the summary neurologic risk score.

Procedures

Assessments included administration of the Mental and Motor Scales of the Bayley Scales of Infant Development[19] at 8, 12, 24, and 36 months (corrected ages). At 3 years, the revised version of the scales was used.[20] The scales yield two separate standard score indices, the Mental Development Index (MDI), reflecting overall cognitive development, and the Psychomotor Index (PDI), reflecting fine and gross motor development, with 100 ± 15 indicating the mean ± 1 SD for each index. Because normative data on the Bayley Scales yield a standard score range restricted from 50 to 150 (± 2 SD), lower scores were extrapolated based on tables developed by Naglieri.[21] The Bayley Scales are widely used for research and clinical purposes with premature infants, and their use allowed for the assessment of both term and preterm infants who varied extensively in their capabilities at 3 years of age. The Bayley Mental Scale administered between 30 and 42 months of age correlates highly (>.70) with other standardized intelligence tests given at the same age.[20]

This study was approved by the institutional review boards of the hospitals that participated, and maternal informed consent was obtained for all subjects.

Analyses

We compared MDI values and PDI values at each age of infants with BPD to VLBW infants without BPD and term infants. For group comparisons of VLBW infants with and without BPD and term infants, within each period, analysis of variance was used with standard scores as the dependent measures, followed by Duncan's multiple range test, which corrects for the number of comparisons. To compare the medical complications of VLBW infants, with and without BPD, t tests for continuous data, χ^2 for categoric variables, or z tests with correction for continuity for proportions were used.[22] For nonparametric data comparison, the Wilcoxon test was used.

To test the hypothesis that BPD predicted poorer developmental outcome after control for demographic and perinatal risk factors, hierarchical multiple regression analysis was used. To assess the total predictive power of BPD versus other medical risk factors, stepwise multiple regression was used.[23] Hierarchical regression analyses allowed control for the effects of other covariates before assessing the effect of BPD, indicating the variance in computation of the predictors that best accounted for outcomes

	(n = 122) n (%)	(n = 84) n (%)		
Minor neurologic malformations	1 (1)	1 (1)	0.1*	1.0
Seizures	8 (7)	0 (0)	5.7*	.02
Echodense lesions	21 (17)	10 (12)	1.1	.30
Porencephaly	4 (3)	3 (4)	0.0*	1.00
Hydrocephalus	11 (9)	4 (5)	1.3	.28
Ventriculoperitoneal shunt	3 (3)	1 (1)	0.4	.64
Meningitis	2 (2)	0 (0)	1.4*	.51
Periventricular leukomalacia	10 (8)	5 (6)	0.4	.54
Neurologic risk score†	0 ± .09	0 ± .01	—	.001‡
Intraventricular hemorrhage	53 (43)	15 (18)	13.9	.01
Grades I–II	35 (28)	12 (14)	5.3	.02
Grades III–IV	18 (15)	3 (4)	6.8	.01

* Fisher's exact test.

† Median ± SE. The neurologic risk score is the sum of all neurologic complications except for intraventricular hemorrhage. Scores ranged from 0–7 for the BPD cohort and 0–6 for the VLBW cohort.

‡ Wilcoxon Test.

RESULTS

Subject Demographic and Neurologic Risk Factors

Infants with BPD were of lower birth weight and gestational age than VLBW and term infants. Race, social class, gender, and maternal marital and educational status did not differ among groups (see Table 1). The BPD group had a higher overall neurologic risk score and more intraventricular hemorrhage (see Table 2).

The sampling strategy yielded adequate numbers of subjects across SES groups so that this variable could be investigated relative to BPD outcomes, ie, for the BPD group at 3 years, 47% were of social class I to III (middle and up) and 53% of IV and V (lower), based on the Hollingshead[16] classification.

In terms of other perinatal complications, BPD infants had increased incidence of ROP (43% vs 4%; $\chi^2 = 39.2$; $P < .001$). The three VLBW infants had grade I ROP. Of the 51 BPD infants with ROP, 19 (37%) had grade I, 12 (24%) grade II, 15 (29%) grade III, 1 (2%) grade IV, and 4 (7%) unknown, using the most severe grade diagnosed eye. Infants with BPD had more patent ductus arteriosus (56% vs 18%; $\chi^2 = 29.7$; $P < .001$), septicemia (47% vs 24%; $\chi^2 = 11.2$; $P < .001$), and lower peak bilirubin (8.3 ± 3 vs 9.1 ± 3, $t = 1.9$; $P < .05$). Consistent with their diagnosis, BPD infants also had higher incidence of apnea (84% vs 65%; $P < .01$), respiratory distress syndrome (94% vs 69%; $P < .001$), and lower Apgar scores at 1 (4.0 vs 5.5; $P < .001$), and 5 minutes (6.3 vs 7.2; $P < .01$). A total of 72% of VLBW infants without BPD had also been on some mechanical ventilation versus 98% of BPD infants ($P < .01$). The majority of infants were inborn (87% of BPD and 91% of VLBW). There were no differences in incidence of necrotizing enterocolitis (4% vs 6%) or in abnormal neonatal hearing results (16% vs 11%). Surfactant was used in treatment of 51 (42%) of infants with BPD and 9 (11%) without BPD. Postnatal steroids were used in treatment of 35 (29%) of infants with BPD and none without.

Developmental Outcome

Infants with BPD achieved standard scores significantly lower than VLBW and term infants on both Bayley Mental and Motor scales at all ages (Tables 3 and 4). MDI scores were in the mentally retarded range (<70) for 18% to 21% of the BPD group at each age, 6% to 11% of the VLBW group without BPD, and <5% of the term group. Motor outcomes were similarly delayed, with 20% to 27% of BPD infants scoring >2 SD units below the mean (PDI <70) at each age tested. Less than 10% of the VLBW group scored in this range, and <3% of the term group. Neurosensory abnormalities were increased in the BPD group, which had more visual impairments (5% vs 0%; $P < .05$) and higher incidence of tracheostomy (3% vs 0; $P < .05$). Groups were not different in occurrence of cerebral palsy (8% vs 2%) or in hearing impairments requiring auditory aids (3% vs 1%). Of the three BPD children with bilateral hearing impairment, one had mild–moderate hearing loss and two had moderately severe loss. The one VLBW child had mild loss.

Adjusted Effects of BPD on Developmental Outcome

We performed hierarchical multiple regression analyses[23] to test the hypothesis that the effects of BPD on developmental outcome remain significant after control for demographic and perinatal risk factors. Hierarchical analyses allowed control for the

TABLE 1. Demographic and Medical Characteristics

	BPD (n = 122) Mean ± SD	VLBW (n = 84) Mean ± SD	Term (n = 123) Mean ± SD	*F*	*P*
Birthweight (g)	956 ± 248	1252 ± 178	3451 ± 526	1633	<.001*
Gestational age (weeks)	27 ± 2	30 ± 2	40 ± 1	1416	.001*
Social class	3.5 ± 1	3.6 ± 1	3.6 ± 1	0.7	.71
Total oxygen (days)†	67 ± 6	4 ± 1	0 ± 0		.001‡§
Race (% white)	55	48	51	1.1	.58
Gender (% male)	52	43	50	1.9	.39
Multiple birth (%)	21	43	10	31.5	.001‖

* BPD < VLBW < T, P < .05.

† Median ± SE.

‡ BPD and VLBW > T, P < .05.

§ Wilcoxon Test.

‖ VLBW > BPD and T, P < .05.

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Age	BPD Mean ± SD	R*	VLBW Mean ± SD	R	Term Mean ± SD	R	F	P
8 Months	92 ± 28	10–145	104 ± 22	38–150	112 ± 19	76–150	17.5	.001†
% < 70	18%		6%		0		21.5	.004†
12 Months	91 ± 29	10–142	104 ± 20	54–134	113 ± 15	74–150	24.1	.001†
% < 70	22%		7%		0		28.8	.001†
2 Years	86 ± 27	16–137	99 ± 24	50–150	107 ± 21	54–150	17.9	.001†
% < 70	26%		10%		1%		29.0	.001‡
3 Years	84 ± 24	10–116	90 ± 16	38–126	96 ± 12	57–127	11.2	.001‡
% < 70	21%		11%		4%		13.1	.001†

* R, range.
† BPD < VLBW and *T*, *P* < .05.
‡ BPD < VLBW < *T*, *P* < .05.

TABLE 4. Bayley Motor Scale Scores (PDI) by Corrected Ages Group

Age	BPD Mean ± SD	R*	VLBW Mean ± SD	R	Term Mean ± SD	R	F	P
8 Months	90 ± 27	10–133	104 ± 22	38–138	112 ± 16	80–150	24.4	<.001†
% < 70	21%		9%		0		23.7	.001†
12 Months	83 ± 25	10–124	100 ± 16	55–132	104 ± 15	62–136	29.6	.001†
% < 70	27%		5%		1%		38.1	.001†
2 Years	84 ± 30	8–141	102 ± 20	33–145	109 ± 14	77–150	31.5	.001†
% < 70	23%		1%		0		38.4	.001†
3 Years	84 ± 29	8–127	98 ± 20	33–122	103 ± 15	58–128	17.6	.001†
% < 70	20%		9%		1%		19.9	.001†

* R, range.
† BPD < VLBW and *T*, *P* < .05.

effects of other covariates before assessing effects of BPD. Control variables included race (white = 0; nonwhite = 1), SES (Hollingshead two-factor index ranging from 1 (high) to 5 (low), multiple birth status (singleton = 0; multiple = 1), gestational age, birth weight, neurologic risk summary score, 0–8 severity of intraventricular hemorrhage, 0–4 patent ductus arteriosus, proven sepsis, ROP (all 0 = absent; 1 = present), and peak bilirubin levels. Race, social class, and multiple birth were entered sequentially and evaluated first, followed by perinatal medical risk variables in the order noted above, followed by presence/absence of BPD (0 = absent, 1 = present) on the final step.

After controlling for other social and medical risk variables, BPD had significant independent effects, predicting poorer motor outcome, and a 10-point decrement in standard score, after all other significant risks were controlled (Table 5). Neurologic risk score and BPD accounted for 21% (*F* = 13.4; *P* < .001) of the variance in motor outcome at 3 years. Once BPD and neurologic risk were accounted for, effects of birth weight and gestational age on motor development were not significant.

Poorer mental developmental outcome at 3 years, in contrast, was predicted by minority race, lower social class, lower birth weight, and neurologic risk score. After control for these risks, BPD did not predict MDI. Only neurologic risk score was a significant medical predictor of mental outcome, however, accounting for 11% of the variance (*F* = 20.7; *P* < .000). Social class and race also significantly in-

TABLE 5. Hierarchical Multiple Regression Analyses of the Effects of Bronchopulmonary Dysplasia on Mental and Motor Outcome at 3 Years

Step	Measure	PDI *b**	PDI SE	PDI *P*	MDI *b*	MDI SE	MDI *P*
1	Race	5.6	4.0	<.17	11.6	3.2	<.001
2	Social class	-.3	2.0	.89	2.8	1.6	.08
3	Multiple birth	1.4	4.5	.75	1.4	3.6	.70
4	Gestational age	1.5	0.8	.06	.9	0.6	.17
5	Birthweight	.01	.008	.05	.01	.01	.05
6	Neurologic Risk Score	13.7	2.4	.001	9.8	2.0	.001
7	Intraventricular hemorrhage	.8	2.3	.73	.5	1.8	.80
8	Patent ductus arteriosus	6.0	4.1	.15	5.1	3.3	.12
9	Septicemia	3.4	3.9	.39	.6	3.2	.86
10	Retinopathy of prematurity	10.6	5.7	.06	5.1	4.6	.27
11	Bilirubin	.2	.8	.85	.5	.6	.48
	R^2		.20			.23	
12	Bronchopulmonary dysplasia	10.0	4.3	.02	3.7	3.7	.32
	R^2		.22			.23	

* *b* Indicates unstandardized regression coefficient

weight did not increase prediction of outcome once neurologic risk was accounted for.

Table 6 presents results from the stepwise regression model ranking risk factors in order of magnitude of effect and the number of standard score (PDI or MDI) points changed by the risk factor. BPD independently accounted for a 12-point decrement in motor score at 3 years, indicating a total effect size of .80, ie, a medium to large effect, whereas neurologic risk yielded an additional 14-point decrement and a large effect size of .93. In terms of mental outcomes, neurologic risk accounted for a decrement of 10 MDI points, exerting a medium effect size of .66, whereas race and social class factors accounted together for a large effect size of .87.

There were differential effects of social class, BPD, and VLBW on mental and motor outcomes. Cognitive outcomes were significantly associated with social class within all risk groups, with a 12- to 22-point difference in cognitive outcome scores between the highest (social class I) and lowest (V) groups, irrespective of infant risk status. Additive effects of low social class, VLBW, and the presence of BPD are illustrated in the occurrence of mental retardation (MDI <70) within social class and preterm groups at 3 years of age. Among children with BPD, 26% of children in SES classes IV and V had MDI scores <70, in contrast to 14% in classes I–III. Among VLBW children without BPD, 19% of children in the lowest social classes were so classified, compared with <2% in classes I–III. For term children, <3% of middle class or higher SES children versus 7% in the lowest social classes were thus classified. There was no impact of social class on motor outcome, however, with standard scores ranging from 83 to 87 across all SES groups for the BPD infants and from 93 to 105 for VLBW and term infants, irrespective of SES.

Some studies have suggested that a definition of BPD reflecting oxygen dependence at 36 weeks' gestational age might better identify infants at risk than the 28-day cutoff used in this study. Therefore, within the BPD group, we compared MDI and PDI scores of infants based on the 36-week definition with those obtained from the current sample. There were no differences in mean MDI or PDI scores at any age tested.

TABLE 6. Effects of Risk Factors on 3-Year MDI and PDI

Risk Factor	Outcome		
	MDI		PDI
	Change in Standard Score	Risk Factor	Change in Standard Score
Neurologic risk score	-10	Neurologic risk	-14
Minority race	-8	BPD	12
Social class	-4		

All other risk factors were nonsignificant; includes above risk factors, as well as multiple birth, gestational age, birth weight, ROP, intraventricular hemorrhage, patent ductus arteriosus, septicemia, and bilirubin level.

The present study investigated the impact of BPD on infant developmental outcome in a prospective, longitudinal study of VLBW and term infants to 3 years of age. BPD was a significant, independent predictor of poorer motor outcome at 3 years of age, confirming previous findings in smaller, less well-controlled samples with shorter follow-up periods.[6-12] These results remained statistically significant after control for confounding demographic and medical variables, with BPD associated with a 10- to 12-point decrement in PDI scores at 3 years, compared with VLBW infants without BPD. Incidence of mental and/or motor retardation[24] reached 21% in the BPD cohort by 3 years, even though sample recruitment was designed to exhaustively recruit the healthiest BPD infants. Our findings indicated that mental retardation was associated primarily with neurologic risk, low social class, and minority race, whereas motor retardation was associated with neurologic risk and BPD. Our sample represents regional outcomes, avoiding the bias of hospital-based studies, and sampling procedures allowed recruitment of a cohort large enough to assess multiple medical and social-demographic risk factors.

Our findings are consistent with Northway's 23-year follow-up of BPD survivors, which found they had an increased history of school delay; used more special education classes; and displayed more abnormalities of coordination, gait, and muscle tone than did cohort controls.[2] Vohr et al, in a 10- to 12-year follow-up study, found that BPD survivors had smaller head circumferences, were smaller in size, and had increased neurologic problems compared with VLBW controls.[6] Robertson et al, in an 8-year follow-up study, found a lower intelligence quotient for those receiving supplemental oxygen for the longest time.[25] Recent school-age follow-up of extremely low birth weight infants also found mental retardation associated with prolonged oxygen dependence, even after birth weight and other neonatal complications were considered.[26] The pathophysiology that leads to infants with BPD having greater developmental delay is probably multifactorial and may include chronic intermittent hypoxia, growth deficiencies, and altered environmental stimulation.[27-29]

Central nervous system pathology in infants with BPD shows brain atrophy and gliosis compatible with chronic hypoxia.[30] Prolonged ventilator and oxygen dependence may result in repeated episodes of hypoxia and acidosis leading to hypoxic–ischemic cerebral injury and increased mortality and morbidity.[31-33] Laboratory confirmation of such chronic hypoxia is seen in the frequent finding of polycythemia. BPD spells secondary to reactive airways or esophageal reflux can be expected to result in chronic episodic hypoxia.

Northway[1] originally perceived that BPD might have significant neurologic ramifications. More recently, Volpe[34] proposed that the spectrum of long-term neurologic correlates in infants with BPD includes selective neuronal injury. Nonprogressive sumed to correlate with cerebral cortical neuronal loss and diffuse white matter injury. Progressive and nonprogressive neurologic disease are less commonly seen, but represent the more severe sequelae of neuronal injury.[34,35]

Observations that deficiencies in home oxygen therapy have been associated with poor weight gain may give credence to the possibility of poor central nervous system growth as well. Clinically unsuspected hypoxia during sleep, sleep apnea, and hypoxic airway constriction have been reported in infants with moderate to severe BPD.[36-38] Recurrent oxygen desaturations have been observed during and immediately after oral feedings in infants with BPD who had been discharged previously from the hospital after weaning from supplemental oxygen.[39]

Finally, environmental factors such as those associated with hospitalization and feeding problems may affect ultimate mental development. Dyspnea and lower respiratory tract infection were more frequent and severe among infants with BPD resulting in more infants with BPD requiring rehospitalization during the first year of life.[40] However, the pronounced effect of BPD on 3-year motor outcome suggests a more direct neurologic insult, in contrast to sociodemographic factors, which affected cognitive function, but was unrelated to motor development in this cohort.

In contrast to motor outcome, 3-year mental outcome was significantly negatively affected by minority race and lower social class, demonstrating the importance of postnatal environmental factors to mental developmental outcome. Consistent with another study,[41,42] the additive effects of BPD, VLBW, low social class, and minority race resulted in higher rates of mental retardation at 3 years in lower SES, African-American children than in children who were not socially disadvantaged. Because 3-year mental outcomes predict school-age academic functioning,[43] our results suggest the need for close follow-up and early intensive interventions for infants with VLBW and BPD, especially among low SES groups. It is encouraging that postnatal environmental factors can have a significant positive impact on BPD and VLBW survivors in mental developmental outcome. Our findings indicate that in terms of mental outcome only, children with history of VLBW and BPD who do not have neurologic sequelae are indistinguishable from VLBW children without BPD at 3 years. Whether the motor deficits associated with BPD at 3 years persist and have implications for the higher rates of learning disabilities in VLBW cohorts at school age needs to be evaluated through longitudinal studies.

New modalities of treatment will not only increase survival of extremely low birth weight infants, but hopefully decrease the incidence of BPD as well. However, currently, increased survival has resulted in growing numbers of infants with BPD.[11] Efforts to prevent prematurity,[15] the increasing use of prenatal steroids,[17] and improvement in treatment modalities for respiratory distress syndrome will all prevent significant respiratory mortality and morbidity. In

monitoring of oxygen and developmental habilitation efforts may help maximize ultimate developmental outcome.

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Neurodevelopmental Outcome in Very Low Birth Weight Infants at 24 Months and 5 to 7 Years of Age: Changing Diagnosis

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We describe the long-term development of 53 very low birth weight premature infants. The children were divided into 2 groups on the basis of ultrasound scan, and classified as: group I, patients with normal ultrasound scan or with uncomplicated hemorrhage; and group II, patients with complicated hemorrhage or only parenchymal lesions. Minor and major sequelae detected at 2 years of age were compared with those observed at 5 to 7 years. Our study confirms that most severely handicapped children are identified by age 2 years. Minor sequelae are more evident at 5 to 7 years and subjects with good outcome, as expressed by a McCarthy General Cognitive Index score > 80, present a discordant cognitive profile with verbal scores higher than performance scores. Therefore, we emphasize the importance of follow-up of very low birth weight premature infants until school age and stress that neonatal ultrasound scan diagnosis of parenchymal damage represents an important diagnostic tool in terms of both short- and long-term neurodevelopmental outcome.

Fazzi E, Orcesi S, Telesca C, Ometto A, Rondini G, Lanzi G. Neurodevelopmental outcome in very low birth weight infants at 24 months and 5 to 7 years of age: Changing diagnosis. Pediatr Neurol 1997;17:240-248.

Introduction

Many studies describe neurologic, cognitive, and behavioral outcome of very low birth weight infants (VLBWI), presenting with potential biological difficulties and developmental problems [1-3].

It is important to identify children at risk of neurodevelopmental problems as early as possible [4]. Improvements in neonatal intensive care have led to a lower mortality rate and to a reduction of major sequelae such as cerebral palsy (CP) in VLBWI, but many studies indicate that these children are at risk of developing neurological abnormalities and developmental problems by school age [5,6].

This finding is confirmed by recent papers [6-8] that report that many infants with no major disability have subclinical motor and cognitive performance deficits which have repercussions on their subsequent education and quality of life. Possible slight damage due to multiple and still unknown adverse influences, such as inadequate nutrition or a disturbance of one or more of the major events in the development of the brain is suggested. Some neurologic problems disappear, others emerge with age [9]. In order to improve the reporting of outcome in VLBWI there is a need to prolong follow-up until school age. On the other hand, long-term follow-up presents other difficulties: a full battery of standardized tests for evaluation of neurologic and cognitive development in a child of 5 to 7 years of age is expensive and time-consuming to administer [10,11].

This study sought to report neurodevelopmental outcome in a group of VLBWI followed-up to the age of 5 to 7 years for the following reasons: to compare the diagnosis at 24 months with that at age 5 to 7 years in order to ascertain the persistence of functional integrity of subjects diagnosed as normal at 24 months; to confirm literature data [12-14] relating brain damage diagnosed by ultrasound scan (US) to neurodevelopmental outcome at school-age as well as at 24 months; and to determine peculiarities of neuromotor and cognitive development of VLBWI at the time of their initial school experiences.

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Patients and Methods

One hundred fourteen patients with birth weight ≤1,500 gm were admitted to the San Matteo Hospital of Pavia from 1983 to 1985. Thirty-five patients (30.7%) died in the neonatal period. Obstetrical and perinatal data were recorded for each infant. Of the 79 survivors, 53 (67%) were monitored until 5 to 7 years of age. Twenty-six (33%) patients were not assessed at school-age: the parents of 10 children refused to participate in long-term follow-up, 7 lived too far away, and 9 children could not be located. There were no differences in the medical perinatal data between the study group and the patients lost to follow-up.

Ultrasound Scan. During the hospital stay, serial US were effected through the anterior fontanelle in both the sagittal and coronal planes with a portable sector realtime scanner (Philips model SDR 2000) equipped with a 5 mHz probe. Scans were performed as early as possible, then at 3, 5, 7, 10, 21, and 30 days and subsequently every 15 days until discharge, and after variable intervals up to 6 months of age. Periventricular-intraventricular hemorrhage was classified according to Volpe [15]. US at discharge were classified according to Stewart et al. [13], as: 1) normal; 2) uncomplicated hemorrhage, i.e., periventricular hemorrhage not associated with parenchymal echodensities or followed by ventricular dilatation or hydrocephaly; 3) complicated hemorrhage, i.e., periventricular hemorrhage associated with persistent parenchymal echodensities or followed by ventricular dilatation, hydrocephaly, or cerebral atrophy, defined as loss of cerebral tissue, through the formation of cysts or irregular enlargement of the ventricular system suggesting periventricular leukomalacia (PVL) or generalized atrophy of the brain. Tiny cysts of < 5 mm in diameter were defined as small focal cystic PVL [5]; and, 4) parenchymal lesions without hemorrhage (e.g. PVL) or cerebral atrophy.

In order to obtain groups which were numerically and prognostically similar [14], the sample was divided as follows: group I: patients with normal US or uncomplicated hemorrhage (n = 23); and group II: patients with complicated hemorrhage or isolated parenchymal lesions (n = 24). Six infants not tested by serial US were not included in the statistical analysis.

Follow-up. Every patient was examined by a child neuropsychiatrist, who was unaware of the ultrasound findings, at 38–42 weeks of gestation (GA) [16].

Follow-up consisted of examinations every 2 months during the first year of life, every 6 months during the second year, and once annually until age 5 to 7 years. Neurologic assessment was performed according to Amiel Tison and Grenier [17], focusing particularly on detection of transient neurologic abnormalities in the first year of life such as anomalies of muscle tone and reflexes normalized by the end of 18 months of corrected age. At 24 months of age the children were considered either neurologically normal, i.e., as having minor neurologic signs such as tone and reflex anomalies or asymmetries without functional deficit, or as having major neurologic signs, e.g., any form of CP. Mental Developmental Index (MDI) was calculated using Bayley Scales of Infant Development [18] at 12 and 24 months of the corrected age.

At age 5 to 7 years, a standardized neurologic examination was performed [4,19] exploring neuromotor functions such as posture, muscle tone, strength, reflexes, oral and digital praxias, graphoesthesia, gnosias, coordination, balance, quality of movements and associated movements and assessing fine manipulative abilities. Children with more than 2 abnormal neuromotor symptoms were classified as having minor neurologic deficits [5]. The parents were asked to complete a questionnaire regarding the child's behavior; this questionnaire gave an overall score which fell in proportion to the increasing number of problems reported.

A cognitive profile was evaluated using the McCarthy Scales of Children's Abilities [20]. This test provides a General Cognitive Index (GCI), as well as 5 separate scores on verbal, perceptual-performance, quantitative, memory, and motor scales. According to McCarthy [20], the cognitive profile was considered disharmonic when the difference between the verbal and performance scores was >11 points. The children's vision and hearing were also evaluated [21,22].

Ophthalmologic and audiometric examinations were performed when necessary to diagnose possible sensory deficits. The former included examination of behavioral response to light and of pupillary reactions, examination of the external eye, cornea, lens, iris, and fundus, a cycloplegic refraction, and evaluation of the ocular motility pattern.

The children were divided into 3 categories according to neurodevelopmental outcome at both 24 months and 5 to 7 years: 1) normal; 2) minor sequelae: minor neurologic signs on neurologic examinations at 24 months and at 5 to 7 years (MDI 71-84 at 24 months and GCI 70-80 at 5 to 7 years), squint and refractive errors; 3) major sequelae: CP and/or mental handicap (MDI ≤70 at 24 months and GCI <70 at 5 to 7 years), sensory-neural hearing-loss requiring active intervention and severe visual impairment (monolateral or bilateral blindness due to retrolental fibroplasia or absence of or poor response to light without other ophthalmologic abnormalities). CP was classified according to Hagberg [23], although the severity of CP was based on functional impairment (mild, moderate or severe) according to Glentig [24].

On the basis of the level of education and occupation of the parents, 4 categories were established to describe socio-economic status: 1. poor socio-economic conditions, i.e., both parents unemployed; 2. modest socio-economic conditions, i.e., both parents manual workers, or only one parent in employment (office worker, clerk, teacher); 3. fair socio-economic conditions, i.e., both parents in employment (teachers, office workers etc.); 4. very good socio-economic conditions, i.e., parents are self-employed or have businesses with a good turnover, professional individuals.

Statistical Analysis. Statistical analysis was performed using the Statistical Package for Social Sciences. Position and dispersion measurements were expressed as 25th, 50th, or 75th percentiles.

The non-parametric Kruskal-Wallis test was used for group comparisons. Multiple comparisons were performed using the Mann-Whitney test corrected by Bonferroni. Friedman's non-parametric test was used for comparing scales, while multiple comparisons of scales were performed using the Wilcoxon test corrected by Bonferroni.

Results

Of the 53 preterm infants, 22 (41.5%) were male and 31 (58.5%) were female. Median GA was 29 weeks (25th percentile: 28 weeks; 75th percentile: 32 weeks) and median birth weight was 1,260 gm (25th percentile: 1,090 gm; 75th percentile: 1,400 gm); 47 infants were of appropriate weight for GA and 6 were small for GA. Forty-seven patients (88.7%) were tested by serial US. Details of US results are given in Table 1.

Group I (normal US or uncomplicated hemorrhage) comprised 23 patients: 10 males and 13 females with median GA 29.5 weeks (25th percentile, 28 weeks; 75th percentile, 32.5 weeks); median birth weight was 1,340 gm (25th percentile, 1,200 gm; 75th percentile, 1,440 gm). Seventeen of these infants were of appropriate weight for GA while 6 were small for GA; 4 of the infants were born at Pavia and 19 were admitted from other hospitals.

Group II (complicated hemorrhage or isolated parenchymal lesions) was made up of 24 patients: 12 males and 12 females with a median birth weight of 1,215 gm (25th percentile, 1,020 gm; 75th percentile, 1,390 gm) and median GA of 29 weeks (25th percentile, 27.2 weeks; 75th percentile, 31.5 weeks); the weight of all these infants (6 of whom were born at Pavia and 18 of whom were transferred to Pavia at birth) was appropriate for GA.

The main perinatal complications in the two groups of

Table I. Ultrasound results

Ultrasound Scan at Discharge	Total Subjects N (%)	Parenchymal Echodensities	Small Focal Cystic PVL	Extensive PVL	Hydrocephaly
Normal	9 (17)				
Uncomplicated hemorrhage	14[*] (26.4)				
Complicated hemorrhage	19[†] (35.9)	5	10	3	1
Isolated parenchymal lesions	5 (9.4)	1	1	3	
Serial ultrasound not performed	6 (11.3)				
Total	53 (100)	6	11	6	1

[*] All grade I.
[†] 14. grade I: 2. grade II: and 3. grade III.

Abbreviation:
PVL = Periventricular leukomalacia

nfants and also in the 6 subjects who were not subjected o serial US are detailed in Table 2.

All the patients who were small for GA were in group ($P < .05$). Respiratory distress and the need for assisted entilation were found to occur more frequently in group I ($P < .05$).

Socio-economic conditions appear to be similarly disibuted among group I and group II patients, as no ignificant differences emerged from the statistical analyis.

Neurodevelopmental Diagnosis. At 24 months of age (Table 3, Fig 1), 29 patients (54.7%) were normal. Minor sequelae had been diagnosed in 13 patients (24.5%): squint or refractive error had been found in 10 children; 2 children were found to have muscle tone and reflex anomalies with no accompanying functional deficit; and 1 child had a MDI score of 75. Major sequelae were diagnosed in 11 children (20.8%): 10 children had CP (9 also with various types of visual disorders), and one child had a MDI score of 63.

able 2. Perinatal data of the total study group and of each of the subgroups classified on the basis of US

Perinatal Data	Total Group (n = 53)	Group I (n = 23)	Group II (n = 24)	Subjects Without US (n = 6)	*P*-Value*
rth weight 50th percentile (gm)	1.260	1.340	1.215	1.300	NS
5th-75th)	(1.090-1.400)	(1.200-1.440)	(1.020-1.390)	(1.162-1.370)	
station 50th percentile (wk)	29	29.5	29	31	NS
5th-75th)	(28-32)	(28-32.5)	(27.2-31.5)	(27.5-32)	
x (Male/Female)	22/31	10/13	12/12	0/6	NS
A/SGA	47/6	17/6	24/0	6/0	<.05
born/Outborn	11/42	4/19	6/18	1/5	NS
spiratory distress (%)	39 (73.6)	13 (56.5)	24 (100)	2 (40)	<.05
sisted ventilation (%)	37 (69.8)	13 (56.5)	22 (91.7)	2 (40)	<.05
tent ductus arterious (%)	7 (12.2)	3 (13)	4 (16.7)	—	NS
nea (%)	22 (41.5)	8 (34.8)	13 (54.2)	1 (20)	NS
idosis (pH < 7.20) (%)	27 (50.9)	10 (43.5)	16 (66.7)	1 (20)	NS
erus (%)	37 (69.8)	14 (60.9)	19 (79.2)	4 (80)	NS
crotizing enterocolitis (%)	4 (7.5)	2 (8.7)	2 (8.3)	0	NS
zures (%)	4 (7.5)	1 (4.3)	2 (8.3)	1 (20)	NS
ection (%)	8 (15.1)	3 (13)	4 (16.7)	1 (20)	NS
io-economic status					
ategory I	—	—	—	—	
ategory II	25 (47.2%)	12	10	3	NS
ategory III	22 (41.5%)	8	11	3	NS
ategory IV	2 (3.8%)	2	—	—	NS
ot possible to assess	4 (7.5%)	1	3	—	NS

lann-Whitney test or Fisher's exact test. *P*-values refer to comparison between groups I and II.

reviations:
A = Appropriate for gestational age
= Nonsignificant
= Small for gestational age
= Ultrasound scan.

Outcome	Total Cohort (n = 53) 24 months	Total Cohort (n = 53) 5 to 7 years	Group I (n = 23) 24 months	Group I (n = 23) 5 to 7 years	Group II (n = 24) 24 months	Group II (n = 24) 5 to 7 years	Group III[†]
Normal (%)	29* (54.7)	16* (30.2)	19* (82.6)	11* (47.8)	5 (20.8)	2 (8.2)	
Minor sequelae (%)	13* (24.5)	26* (49)	4* (17.4)	12* (52.2)	8 (33.3)	11 (45.9)	
Major sequelae (%)	11 (20.8)	11 (20.8)	0*	0*	11* (45.9)	11* (45.9)	
MDI/GCI 50th percentile	92*	99*	93*	100*	83.5	86	
(25th-75th)	(80.5-98)	(81.5-112)	(88-98)	(97-116)	(55-96.5)	(49-104)	
Visual disorders (%)	19 (35.8)	19 (35.8)	4* (17.4)	4* (17.4)	14* (58.3)	14* (58.3)	
Epilepsy (%)	3 (5.7)	3 (5.7)	—	—	3 (12.5)	3 (12.5)	

* $P < .05$.

[†] Group III (no ultrasound scan): 5 (83.3%) of the 6 subjects were classified as normal at 24 months of age and 1 (16.7%) had minor sequelae (squint). At 5 to 7 years of age 3 (50%) children were judged to be normal and 3 (50%) to have minor sequelae.

Abbreviations:
GCI = General Cognitive Index
MDI = Mental Developmental Index.

Visual disorders emerged in 19 patients (35.8% of the total group): squint was found in 13 patients (24.5%, 9 with minor and 4 with major sequelae), refraction anomaly in 9 (16.9%, 4 with major and 5 with minor sequelae), and fundus anomalies in 6 (11.3%). Different combinations of these abnormalities were found in 9 children (16.9%). Severe visual impairment was diagnosed in 5 patients (9.4%), all with CP. No children revealed hearing disorders. Generalized epilepsy was found in 3 patients (5.7%).

At age 5 to 7 years, 16 children (30.2%) were confirmed normal, while 13 patients, classified as normal at 24 months presented minor neurologic anomalies and were included in the minor sequelae group, which increased to number 26 patients (49%) ($P < .005$). There was no change in the diagnosis at 5 to 7 years in 11 children (20.8%) who presented major sequelae at 24 months.

There was no change in the number of patients with visual disorders (19, 35.8%) or epilepsy (3, 5.7%) at the end of the follow-up.

Group I. As far as the 23 group I children are concerned (Table 3 and Fig 2), 19 patients (82.6%) were diagnosed as normal at 24 months, while 4 patients (17.4%) revealed minor sequelae (squint). At the age of 5 to 7 years, 11 patients (47.8%) presented a normal outcome, while 8 children (3 with normal US and 5 with bilateral uncomplicated hemorrhage) revealed more than two anomalies on neurologic examination and were included in the group with minor sequelae; the total number of minor sequelae in group I was therefore 12 (52.2%).

Statistical analysis revealed that the drop in the number of normal diagnoses and the increase in the incidence of minor sequelae at age 5 to 7 years were both significant data ($P < .05$). No major sequelae emerged at either 24 months or 5 to 7 years in group I. Visual disorders remain stable (both at 24 months and at 5 to 7 years). No epilepsy was found in group I.

Group II. In group II (Table 3 and Fig 3), 5 patients (20.8%) were considered normal at 24 months. Minor

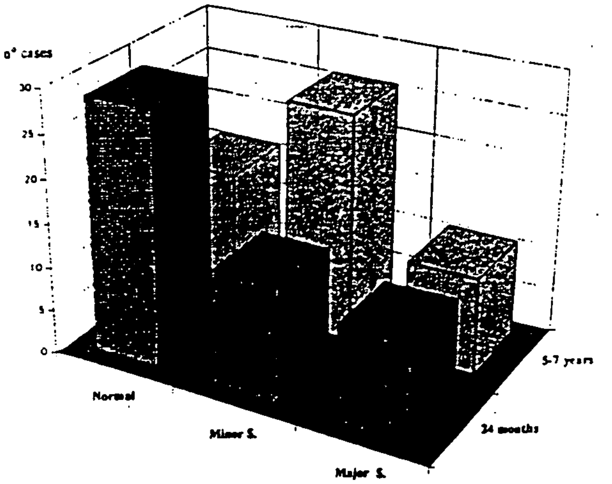


Figure 1. Neurodevelopmental outcome of total cohort (53 subjects) at 24 months and at 5 to 7 years of age. P < .05.

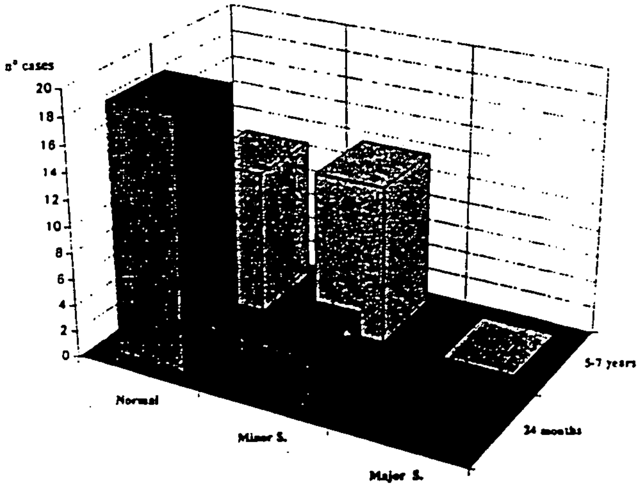
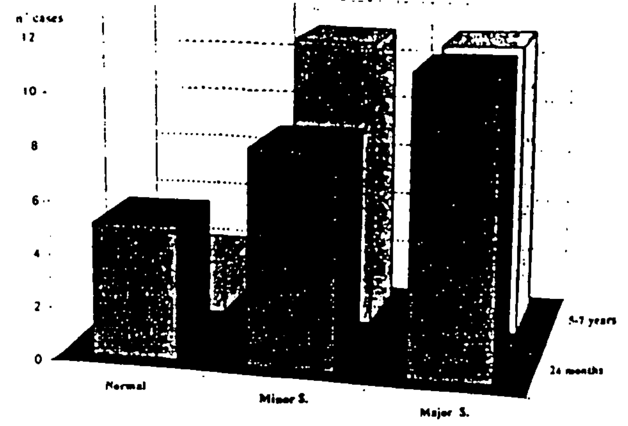


Figure 2. Neurodevelopmental outcome at 24 months and at 5 to 7 years of age in group I. N = 23; P < .05.



igure 3. *Neurodevelopmental outcome at 24 months and at 5 to 7 ears of age in group 2. N = 24;* P, *not significant.*

equelae were diagnosed in 8 patients (33.3%): these cluded 5 children with visual disorders (4 cases of squint nd 1 of myopia), 1 child with a MDI score of 74 and 2 hildren with muscle tone and reflex anomalies without nctional deficit.

Eleven patients (45.9%) developed major sequelae: 1 ild had a MDI score of 63 and there were 10 patients ith CP. The latter included 6 cases of tetraplegia (5 vere and 1 moderate), 2 cases of diplegia (one mild and e other severe) and 2 cases of hemiplegia (one moderate d one mild). With one exception, all the patients with P developed visual disorders (4 squint and refraction omalies and 5 severe visual impairment). Furthermore, of these children also developed generalized epilepsy.

At age 5 to 7 years, 2 children (8.2%) were once again gnosed as normal while 3 (2 with small focal cystic L in the left hemisphere and 1 with small focal cystic L in the right hemisphere), who had presented with re than two neurologic anomalies, were included in the up of patients with minor sequelae. At the end of low-up, the number of group II children in this category s 11 (45.9%). At 5 to 7 years of age, major sequelae re once again diagnosed in 11 patients even though the sibility of improvement was not excluded in several es. In particular, 1 child with severe tetraplegia had ieved good functional use of the arms and was classi- as diplegic at age 5 to 7 years; the diplegia of another ld, who managed to walk independently and scored a I of 107, was considered mild at the end of the ow-up; and the child with mild hemiplegia also man- d to walk independently and displayed an excellent I score at school-age (GCI = 122).

isual disorders and epilepsy remained stable at 24 ths and 5 to 7 years. We stress that major sequelae and al disorders are both significantly present in group II $< .05$).

leanwhile, no statistically significant differences rged in group II between the ages of 2 and 5 to 7 years. (83.3%) of the 6 patients who did not undergo serial were classified as normal at 24 months (4 with transient neurologic abnormalities in the first year of life). 1 child (16.7%) had a squint. At the end of follow-up, 3 patients (50%) were judged to be normal and 3 (50%) to have minor sequelae.

Cognitive Development. As shown in Table 3, the median MDI score of the 53 children at 24 months of age was 92 (25th percentile, 80.5; 75th percentile 98) and the median GCI score at 5 to 7 years of age was 99 (25th percentile, 81.5; 75th percentile, 112); in group I the median MDI score was 93 (25th percentile, 88; 75th percentile, 98) and the median GCI score was 100 (25th percentile, 97; 75th percentile, 116). The improvement in cognitive performance between 24 months and 5-7 years proved significant upon statistical analysis.

The median MDI score in group II was 83.5 (25th percentile, 55; 75th percentile, 96.5) and the median GCI score was 86 (25th percentile, 49; 75th percentile, 104) without significant differences.

Table 4 presents cognitive profiles detailing 25th, 50th and 75th percentiles of GCI scores, and of subscale scores of the total cohort and of each of the groups. The median GCI score in group I (100) was higher than that in group II (86) ($P < .05$). A similar difference between the two groups also emerged between the median scores in the verbal scale (57 vs 45), the memory scale (54 vs 48), the quantitative scale (52 vs 41) and the motricity scale (49 vs 40). A less marked difference, which was not significant, emerged between the two groups in relation to the performance scale. Twenty-three children (43.4%, 13 in group I, 8 in group II, and 2 subjects without serial US) showed a disharmonic profile, with a difference of more than 11 points between verbal and performance scales.

Furthermore, when comparing the scores obtained in the different subscales (looking both at the total cohort, and at each subgroup separately), a discrepancy emerged between the higher verbal and memory scores, and the lower performance and motricity scores, as illustrated in Figure 4. This difference proved to be significant in relation to the group as a whole (chi-square = 17.6898; $df = 4$; $P = .0014$) and in relation to group I (chi-square = 14.4364; $df = 4$; $P = .0060$), while within group II, it was less marked and not significant.

Discussion

The results of our follow-up investigations are of no epidemiological value. Our aim was not to "count" the sequelae, but rather to carry out a longitudinal study of a group of VLBWI in order to compare the diagnosis made for each child at 24 months, with that made at school-age.

As far as the perinatal data are concerned, children who developed signs of parenchymal damage (group II) showed more perinatal complications, in particular, respiratory distress (especially bronchopulmonary dysplasia) and need of assisted ventilation were statistically significant, in accordance with data in the literature [25,26]. No relevant differences emerged between the two groups

Table 4. Cognitive development at 5 to 7 years in VLBWI

	Total Cohort (n = 53)	Group I (n = 23)	Group II (n = 24)	Subjects Without US (n = 6)	*P*-Value*	Mann-Whitney Test
GCI 50th percentile	99	100	86	114.5	<.05	U = 149
(25th-75th)	(81.5-112)	(97-116)	(49-104)	(105-122)		*P* = .0068
Verbal 50th percentile	55	57	45	58	<.05	U = 122.5
(25th-75th)	(44-60)	(51-62)	(21-57)	(54-66)		*P* = .0051
Memory 50th percentile	51	54	48	53	<.05	U = 137
(25th-75th)	(43-56)	(48-60)	(27-52)	(45-58)		*P* = .013
Quantitative 50th percentile	48	52	41	54.5	<.05	U = 153
(25th-75th)	(41-58)	(44-58)	(24-53)	(45-66)		*P* = .037
Motricity 50th percentile	47	49	40	62	<.05	U = 105
(25th-75th)	(36-54.5)	(42-63)	(21-47)	(45-74)		*P* = .02
Performance 50th percentile	45	45	43	52.5	NS	—
(25th-75th)	(41-51)	(43-61)	(21-75)	(46-61)	NS	—
Disharmonic profile (%)	23	13	8	2	NS	—
	(43.4)	(56.5)	(33.3)	(33.3)		

* *P*-values refer to comparison between groups I and II.

Abbreviations:
GCI = General Cognitive Index
NS = Nonsignificant
US = Ultrasound scan.

regarding socio-economic status. While various investigators agree that medical-biological variables have a more direct influence in the short-term [27,28], it may be that by the time a patient had reached school-age, environmental factors which are virtually impossible to quantify, have exacerbated, or on the contrary, attenuated significantly the consequences of unfavorable pre-perinatal events [29].

Neurodevelopmental Diagnosis. In accordance with the literature [12,13,30], we also found that the most severe neuromotor and cognitive defects causing disability could be identified early, and that they correlated strongly with the US diagnosis of parenchymal brain damage (all major sequelae belonged to group II). Furthermore, we found that major sequelae remain stable over time until school age. This does not exclude, however, the possibility of functional improvement or that some of these patients may be able to attend primary school. These findings mean that preterm infants with no detectable major impairments at 24 months will not have major sequelae due to prematurity at age 5 to 7 years.

The number of minor sequelae was higher at 5 to 7 years of age than at 24 months: in a high and statistically significant percentage of cases, children judged normal at 24 months of age were no longer found to be so when reviewed at school-age. Literature reports similar findings [9,31-34]; the increase in the number of minor sequelae diagnosed at school-age is due mainly to the emergence of "minor neurological signs." Recent articles have reported similar neurologic deficits at 5 to 7 years of age in VLBW children who had US signs of periventricular white matter involvement, such as small cysts [5,35] or persistent periventricular hyperechogenicity [7]. In our study, the

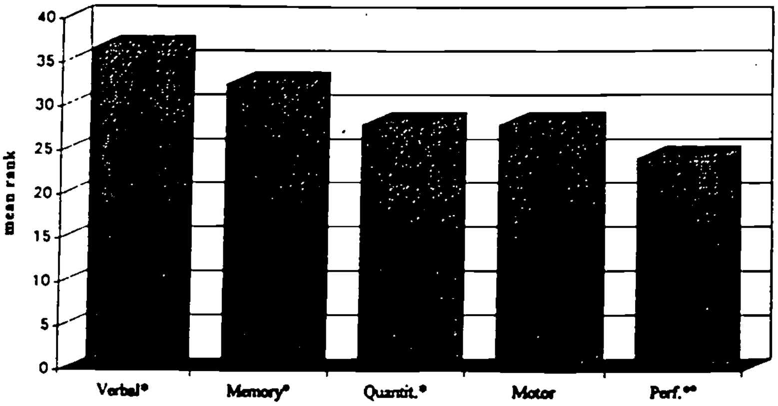


Figure 4. Cognitive profile and McCarthy's Subscales in total cohort. N = 53. Chi-square = 17.6898; df = *4:* P = *.0014.* *$P < .05$*, Verbal vs Perf.; Verbal vs Quantit.* °$P < .05$ *Memory vs Perf.*

emergence of minor neurologic signs in school-age patients occurred above all in the group of children with normal US or with uncomplicated hemorrhage, while the increase in minor sequelae among subjects with a clearly abnormal US was less marked and not statistically significant. It is, therefore, precisely those children who present none of the major risk factors and give us no cause for concern at 24 months of age who go on to develop motor difficulties (albeit slight and non-invaliding ones), by the time they reach school-age. It is very difficult to attribute the appearance of a neurological deficit to the socio-economic status of the family, while this factor is much more likely to affect the child's cognitive development [31]. Our long-term results appear to be in accordance with findings recently reported by Levene et al. [6] and van de Bor et al. [34]. It would doubtless be interesting to analyze the presence and stability of minor sequelae, but it must be remembered that our sample is too small to enable us to reach definite conclusions on eventual differences in minor neurologic signs between patients with normal US and those with uncomplicated hemorrhage, and/or between the side and site of lesions.

A methodological problem arises from this increase in minor sequelae. While on one hand, neurologic investigations performed in newborns and in the first year of life are strictly coded, and at age 5 to 7 years we can enjoy the collaboration of the child and are able to analyze in detail their motor [4,36] and cognitive [20] abilities, examina-ions performed in toddler-age children are not so straight-orward. Often we have to limit ourselves to observation f the patient and minor neurologic signs may go unno-iced in this age group simply because we do not have a ufficiently sensitive means of neurologic assessment at ur disposal. The application of recent methods for the ualitative assessment of the motor repertoire of toddlers 37], and attempts to identify mild neurologic signs that ersist throughout childhood [38], may help to resolve this roblem.

Another interesting result emerging from our patients' eurological diagnoses is the high frequency of visual isorders among the minor sequelae already evident at 24 onths of age and present, sometimes as the only clinical gn, above all in children with US diagnosis of parenchy-al damage. Many authors [39,40] describe the vulnera-ility of the visual system in terms of both peripheral oblems (retinopathy and strabismus) and central prob-ms (from the serious "cerebral visual impairment" to e less clear and less easily demonstrated visual-percep-on disorders); visual problems are especially evident in ose patients with cystic leukomalacia or with signs of volvement of the occipital areas and may be important to eir prognosis, especially in the long-term.

We realized that in our cohort visual deficits included a ixture of problems, central and peripheral. In order to in a better understanding of these types of sequelae, ch problems need more accurate diagnosis using more ecific methodological follow-up instruments. Some, which we now have at our disposal, such as visual acuity cards [41], were not available at the beginning of follow-up. This inevitably places a limitation on studies like ours, which are conducted over a very long period of time.

Cognitive Development. Looking at cognitive development, the first interesting finding to emerge from our study is the statistically significant increase in the GCI at school-age in relation to the Developmental Quotient recorded at 24 months of age, a fact that appears to reflect an improvement in the cognitive abilities of our VLBWI. It should also be pointed out that other investigators agree [42] that the McCarthy scale, among those indicated for use with children of school-starting age, is the one which correlates most with the Bayley scale. Once again the change, this time an improvement, was most significant in children with normal US or with uncomplicated hemorrhage.

The better cognitive abilities of group I children are also seen when comparing the median scores of the various McCarthy subscales which, with the exception of the perception performance subscale, are all higher (and always statistically significantly so) in group I. Another finding is particularly interesting: the difference between the two groups is less marked in the performance scale, which would appear to indicate that it was precisely the skills investigated by this scale which were the ones most impaired in the so-called "normal" children.

Indeed, an analysis of the cognitive profile in each group confirms this clinical impression. Taking both the total population and, in particular, the patients in group I, there is a statistical difference between the five McCarthy subscales, and the abilities measured by the verbal and memory scales are better than those measured both by the quantitative scale and, particularly, by the performance scale.

The results of Roth et al.'s population [43,44] are very similar to ours and show that the verbal skills of VLBWI at the age of 8 years are clearly superior to their performance skills, even in children whose brain US was normal. The same author [43,44] hypothesizes that this peculiar cognitive profile depends on sub-optimal right hemisphere functioning. This is the hemisphere that controls performance skills [45,46]. This may be due to damage to interhemispheric connections, for example by minor degrees of PVL affecting the posterior corpus callosum, which is involved in the interhemispheric transfer of cognitive information [47]. In fact, signs of hypoxic-ischemic impairment in preterm infants are often present in posterior periventricular regions, and milder cases of this parenchymal alteration, which could involve the callosal fibers, are not identifiable by US [48].

There are many other factors which have a part to play in determining a cognitive profile. As pointed out by Mutch et al. [49], between the 26th and 34th week of GA the physiological processes of neuronal death and dendritic retraction are at their most intensive, giving rise to increased metabolic activity, and thus increased vulneracerebellum, and optic radiations, all of which are areas involved in important and central aspects of movement control. These areas are, furthermore, especially sensitive to ischemic-hemorrhagic insults and cerebral circulatory disorders; every interruption of these circuits as a result of one or more pathologic factors could easily be responsible for altering performance, in functionally diverse ways, during development.

The brain is, in its initial post-natal phases of development, particularly vulnerable to malnutrition, and the quality of the diet in the first few weeks of life could, in preterm infants, represent a further factor influencing the child's future cognitive development [50,51].

Marlow et al. [52] believe that less than optimal motor performances on starting school represent a reliable indicator of probable future educational difficulties, especially in the area of mathematics. Perhaps, as already reported by other authors [53], in our sample too, the lowest scores recorded in the quantitative scale are an expression of the beginning of difficulties in this area.

Our VLBWI seemed to have good short-term memories, as underlined by the relatively higher scores recorded in the memory scale. This feature, however, does not correspond with the results of other studies [49] which, using more sophisticated tests, reveal problems of memory and attention in VLBWI and, in accordance with what has been proven in animal models, correlates these with signs of hippocampal gray matter impairment, the hippocampus probably being involved in the transformation of short-term memory into long-term memory.

Our study confirms that most handicapped children are identified in the short term: major sequelae diagnosed at 24 months of age are still present at age 5 to 7 years and a neonatal US diagnosis of periventricular parenchymal damage constitutes an important predictive factor in these cases. Positive diagnosis of minor sequelae increases from 24 months to 5 to 7 years of age: therefore, we emphasize the importance of school-age follow-up of these children which permits assessment of "soft" neurologic signs, which may have been missed at 24 months. This failure to detect minor sequelae may be a result of the diagnostic gap due to the non-specificity of the neurologic examination in toddler-age. Children with good cognitive outcome expressed by a GCI score >80 present a disharmonic cognitive profile, with verbal scores higher than performance scores. These findings suggest possible slight damage of periventricular parenchymal pathways, not detectable by US and due to multiple adverse factors, such as inadequate nutrition, which may have affected myelination. These considerations represent a definite stimulus for more detailed studies of cognitive function in VLBWI.

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APPENDIX F

Family Centered Care Module

Family Centered Care

Module one in a series of seven designed to introduce primary health care providers to early intervention and special education services delivery systems.

Developed by:
The Division of Child and Family Studies
Department of Pediatrics
University of Connecticut Health Center

TABLE OF CONTENTS

INTRODUCTION

The philosophy of Family Centered Care is the basic foundation for the Children with Disabilities curriculum. As a physician working with children, it is essential to have an understanding of the impact disabilities or special health care needs can have on a family. This module is designed to inform you, the pediatric resident, of this impact and to support you in gaining an appreciation of the central role a family has in the provision of care for their child. You will learn the nine principles of Family Centered Care and how their implementation assists and supports the needs of the family in the delivery of services to children. The importance of cultural competence and its elements will be discussed as well as family systems theory and The Medical Home model. You will gain first hand knowledge of the impact of disability on the family when you visit two families in their homes, one being a patient from your own continuity clinic.

ORGANIZATION OF MODULE

The Family Centered Care module is divided into four components. The first is a didactic component about the principles of Family Centered Care. During this didactic component a panel of parents will discuss the impact of having children with special health care needs and their perspectives on the health care system. The second component requires you to conduct a home visit with a family whose child has disabilities or special health care needs. The third component, very similar to the second, requires you to conduct a visit to one of your own continuity clinic patient's home. This patient must have disabilities or special health care needs. The fourth component requires you to interview a family attending a specialty clinic to learn about a child's care from the family's perspective.

Summary of organization of module:

- One half day didactic
- One half day home visit arranged by Division of Child and Family Studies
- One half day home visit with child from continuity clinic (to be arranged by resident)
- One half day specialty clinic visit

OBJECTIVES

At the completion of the Family Centered Care module, you will be able to:

1. Learn and apply the nine principles of Family Centered Care to the health care delivery system and to interactions with families and patients.
2. Describe cultural competence and how cultural differences impact one's work with children and families.
3. Explain how the Family Systems Theory relates to family reactions to disability, father and child interactions, and sibling interactions.
4. Describe how lifespan issues can be especially difficult for children with disabilities and their families.
5. Define The Medical Home and describe the benefits for children with special health care needs or disabilities.
6. Utilize the Family Center at Connecticut Children's Medical Center as a resource.

COMPONENT ONE: INTRODUCTION TO FAMILY CENTERED CARE

Location and Times:

The Family Center,

Connecticut Children's Medical Center, Fifth Floor

Telephone:	(860) 545-9023
Morning Sessions:	8:30 AM to 12:30 PM
Afternoon Sessions:	1:00 PM to 5:00 PM

Format:

Information will be presented through discussion, reading materials, case studies, and panel presentation. Videos are optional.

Resident's Responsibilities:

Please arrive on time and come prepared to participate in the conversation. It will be a more productive session if you have read the materials beforehand. Be prepared to critique the session afterwards.

OUTLINE OF SESSION

I. Parent Panel or The Family Center Staff
  A. Overview of family and child issues

II. Family Study

III. Philosophy of Family Centered Care
  A. Nine Principles of Family Centered Care
  B. Cultural competence
    1. Developing cultural self-awareness
    2. Gathering culture-specific information

IV. Family Systems Theory
  A. Family reactions to disability
  B. Father and child interactions
  C. Sibling interactions
  D. Lifespan issues

V. Medical Home Model
  A. Services within the medical home
  B. Benefits of the medical home

VI. The Family Center at CCMC

VII. Family Study - Revisited

- A. Discussion questions
- B. Discussion question answers
- C. Resolution

Note: Throughout the session the family panel provides their own real life experiences to exemplify the concepts discussed.

Related Readings:

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Trawick-Smith, J. W. (1997). Early childhood development: A multicultural perspective. New Jersey: Prentice Hall, Inc.

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Related Videotapes:

Atkins, P. (Producer/Director). (1988). Family-Centered Care [Videotape]. (Available from the Association for the Care of Children's Health)

Fullerton, W. (Producer/Director), & Brock, W. (Director). (1991). Heart to Heart: Parent/Professional Communication [Videotape]. (Available from Breaking Down the Barriers, Kentucky Developmental Disabilities Planning Council, Division of Mental Retardation, Cabinet for Human Resources, 275 East Main Street, Frankfort, KY 40621)

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FAMILY STUDY

JP is about to be discharged from the newborn intensive care nursery after a twenty-week hospitalization following his premature birth. Shortly after birth (at 72 hours), he developed seizures which were subsequently controlled by medication. He required ventilation for three weeks. He also had difficulty feeding by mouth. His mother, Pilar, is a seventeen-year-old single parent in good health. Pilar is from the Philippines. She works an average of 30 - 40 hours a week, with no insurance benefits, as a secretary for a temporary employment agency. Pilar must continue to work after JP comes home, and would like to find a permanent position with benefits. She worries about how she will pay for all of JP's needs.

Pilar lives alone, and JP's father is not involved with the family. She has no family living nearby to assist her with JP's care; however, Pilar does have a few close friends here from her country who have visited JP with her at the hospital. Pilar will need support in making decisions about, and providing care for JP. It is a custom in the Philippines for parents not to question a physician's opinion about medical care.

When Pilar was able to visit JP she often sat and rocked him for hours. She missed some visits which made it difficult for the hospital staff to adequately train Pilar in JP's care. In addition, Pilar's English is not clear and there exists a language barrier. However, toward the end of JP's hospitalization, Pilar arranged for two days and one overnight at the hospital so she could learn JP's care plan and participate in the discharge planning process.

Pilar lives in a one-bedroom apartment across town from the hospital. She does not have a telephone, so maintaining contact with the hospital was difficult. JP has a number of ongoing medical concerns, including the need for seizure medication and assistance during feedings. Because his muscle tone is poor, he is unable to suck for long periods. His caloric intake must therefore be monitored to make sure he gains enough weight.

Pilar is committed to having him with her, but has a number of questions she would like answered before she takes JP home. The hospital social worker is concerned about Pilar's ability to adequately care for JP. As the community pediatrician who will be caring for JP, you are responsible for making sure the transition to home goes smoothly.

PHILOSOPHY OF FAMILY CENTERED CARE

Family Centered Care is a philosophy of care that encompasses family centered, community based, coordinated services for a child with special healthcare needs and his or her family developed by the former Surgeon General, C. Everett Koop, M. D., Sc. D. A major premise of this approach is that the child is part of a family, and that the family has great impact on the development and well-being of the child. A family centered approach to providing services to a child and his or her family requires a relationship based on mutual trust and respect to be established and maintained between professionals and the family. There are nine principles of Family Centered Care with the underlying premise being to develop a system that: 1) assists in the delivery of services to children with special healthcare needs, and 2) supports the needs of the family.

The family centered approach may represent a shift in orientation for some physicians and professionals in other fields. It is important that healthcare professionals become familiar with the family centered principles to ensure that the services being provided meet both the child's and the family's needs.

NINE PRINCIPLES OF FAMILY CENTERED CARE

1. **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.**

   As a child grows and moves through the service delivery system, he or she will be involved with many professionals, specialists and agencies.

However, the family will be the constant in the life of the child. It is essential that professionals recognize and respect the central role that the family plays in the care of their child. Ultimately, each family must assume responsibility for their child's life. Professionals must learn to work in partnership with each family, valuing their judgment, and respecting their values.

2. **Facilitation of parent/professional collaboration at all levels of health care.**

   Successful care plans must be developed through meaningful collaborations to reflect each family's strengths and be tailored to each family's needs. The ultimate success of this process depends on the ability of parents and professionals to work together in partnership.

3. **Sharing of unbiased, complete information with the parents about the child's care on an on-going basis.**

   A true partnership between parents and professionals requires that parents have access to information which is communicated in an understandable way and in the family's primary language. This information includes: diagnosis and prognosis; available resources, including funding for services; and current research data.

4. **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of the family.**

   Every family is unique. Each family's need for support reflects unique values, strengths, coping styles, and hopes for the future. Family support protocol suggests that families have access to information and resources to enable them to maintain the integrity of their family system. Family needs may include funding, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, assistive technology, housing modifications, and advocacy.

5. **Recognition of family strengths and individuality with respect for different methods of coping.**

   Each family has its own strengths and sources of support. These may include neighbors, extended family, friends, and community associations. Professionals should work with the family to identify support networks and develop strategies to strengthen and reinforce them. In addition, each family is defined differently and may include friends, as well as grandparents, brothers, sisters, aunts, and uncles. Services must be tailored to fit around this unique family system with its own specific goals, visions, values, culture, and coping style.

6. **Understanding and incorporating the developmental needs of infants, children, and adolescents, and their families into health care systems.**

   A medical plan must address other issues in addition to each child's health care needs. Each family system should have access to opportunities for socialization and community support. The medical home allows each family member to fulfill his or her role, and support each child with opportunities to be a part of family and community life. Please see Appendix A for a fact sheet on how to communicate with people with disabilities and a list of common acronyms and abbreviations.

7. **Encouragement and facilitation of parent-to-parent support.**

   Support from other families is valuable in developing successful coping strategies. Parent-to-parent support may involve matching experienced or veteran parents with a parent newly referred into the service delivery system. The veteran parents receive training in their roles as parent-to-parent support group volunteers, and each parent-to-parent support group is coordinated by a parent. Family supports can also include parent groups led by professionals.

8. **Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.**

   It is critical that service providers be able to respond to the ever-changing needs of each child and family with a flexible, accessible, and responsive system of services. Families often report that inflexible service systems and friction between parents and professionals are greater sources of stress than the daily care of their children. They report stresses such as rigid and conflicting eligibility criteria; confusing application forms; turf battles among agencies and service providers; and a fragmented, difficult-to-access system of services.

9. **Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.**

   Each family has its own beliefs, values, strengths, and needs. Professionals need to guard against imposing their own values or cultural expectations upon the family. Care plans must enhance the family's strengths and address only those needs which the family itself has identified, rather than those which professionals believe exist.

PROVIDING FAMILY CENTERED CARE

Questions To Ask Yourself

Topic	Questions
Family is Constant	♦ Have I identified the family's needs? ♦ What can I do to help meet their needs? ♦ Have I solicited the family's input? ♦ Have I taken the family's needs into account when making recommendations?
Collaboration	♦ Have I met with or contacted other professionals serving this family? ♦ Have I let the family and other professionals know how to contact me?
Information	♦ Have I been honest in providing the family with information about their child's condition? ♦ Have I been supportive to the family, helping them to adjust to the needs of their child? ♦ Have I presented all information in a clear and understandable way and in the family's primary language?
Policies and Programs	♦ Have I informed the family of agencies and services that can help assist them with issues related to the care of their child (for example, funding, education, service coordination, parent-to-parent support, transportation, adaptive equipment, housing modifications, and advocacy)?

Topic	Questions
Strengths and Individuality	◆ Have I helped the family identify its strengths? ◆ Am I aware of the individual needs of this family?
Developmental Needs	◆ Does the treatment I prescribed support the more "typical" developmental and lifespan needs of the child and family?
Support	◆ Have I encouraged the family to seek out the support of other families and agencies?
Health Care	◆ Have I clearly informed the family of the services for which they qualify? ◆ Have I collaborated with other professionals involved with this family to make sure the family is aware of all possible services that they qualify for? ◆ Have I responded to the family's needs?
Values	◆ Have I considered the family's culture and values when prescribing the treatment?

CULTURAL COMPETENCE

Best practices in working with families call for open, supportive, and responsive environments in which differences are valued and encouraged. Cultural competence requires awareness, appreciation, and respect for diversity and the capacity to recognize and respond to the needs of those who are different from oneself. Cultural competence requires one to adapt and accommodate their work to the values, behaviors and expectations of others cultural beliefs and practices. Optimally, professionals should view inter-cultural interactions as learning opportunities and use cultural resources in their intervention practices.

The term cultural describes the patterns of behavior, communication, customs, beliefs, values, and institutions of a specific racial, ethnic, religious, social, or even professional group. Cultural identity exerts a strong influence on how people live. However, other factors also shape the ways in which individuals and families live and how they identify themselves. These additional factors include:

- Socioeconomic status
- Educational level
- Age
- Gender
- Pre-migration and migration experiences
- Vocational or professional status
- Language proficiency
- Physical characteristics
- Sexual orientation
- Family composition
- Proximity to other members of their cultural group
- Disability or health care status

The elements of cultural competence include:

- Self-awareness and awareness of the "dynamics of difference" (including understanding "culture" and its function in human behavior).
- Knowledge of culture-specific information pertaining to various ethnic groups.
- Skills necessary to engage in successful cross-cultural interactions with culturally diverse populations.

Developing cultural self-awareness

An understanding of how one's own cultural beliefs and practices impact behavior, motivation, and opinions can be developed by exploring one's own cultural heritage. Discussions with older family members about their memories of past events; examining family albums, journals, and documents; and gathering information about activities, customs, celebrations, and events are helpful in painting a picture of what values and beliefs make up an individual's cultural heritage. Once an individual has discovered the values and beliefs that make up his or her cultural heritage, it is important to reflect on them to understand how they influence one's behavior, motivations, and opinions. Having a clear understanding of the way in which one's own values and beliefs influence behavior helps the individual understand how the behaviors of others reflect their cultural values and beliefs.

Gathering culture - specific information

Professionals need to become familiar with the cultural values, beliefs, traditions, and customs of families from diverse backgrounds. In particular, they need to gather culture-specific information related to a family's views of children and child rearing practices; its structure and the roles of its members; disability and its causes; health and healing practices; and views of change and intervention.

There are four ways to gather culture-specific information:

- Learn by studying and reading about a culture, including history, geography, poetry, biography, and fiction.
- Talk and work with individuals from a particular culture who can act as cultural guides and mediators.
- Participate in the daily activities of another culture through celebrating holidays, community projects, or joining in worship practices.
- Learn the language of that culture.

Acquiring knowledge about specific cultural practices, beliefs, and customs is a large undertaking that requires a great deal of observation, study, and reflection. Learning information about a particular culture, including its values and beliefs, behaviors, and customs, should not lead one to conclude that all people who belong to that culture fit into that particular stereotype.

Rather, cultural competence involves recognizing, understanding, and respecting cultural differences that impact any individual's behavior, thoughts, beliefs, and practices. Professionals should not make assumptions about a family's concerns, priorities, and resources based on their cultural identity.

FAMILY SYSTEMS THEORY

The family is not simply a collection of individuals but a complex system. To understand a family, it is not enough to know who the members are. The experience of living in a family involves the emotional bonds and interaction patterns that exist among family members. It also includes the family's history, values, goals, dreams, and belief systems. Finally, it involves interactions outside the family.

Family Systems Theory is a transactional theory in which each of the components of a system have an effect on any or all of the other components in that system.

Five concepts basic to a family systems perspective include:

- The family as a system is more than the sum of its parts.
- Change in one part of the family affects the entire family system.
- Subsystems are embedded within the larger family system.
- The family system exists within a larger social and environmental context.
- Families are multigenerational.

FAMILY REACTIONS TO DISABILITY

Reactions to the diagnosis of disability or chronic illness are as varied as families are themselves. These reactions can be impacted by cultural beliefs, religious practices, socioeconomic status and the availability of and comfort with using support systems, both formal and informal.

Common feelings experienced by family members are: fear, anger, loneliness, resentment, embarrassment, and guilt. These feelings often occur at the time of initial diagnosis or recognition of the illness or disability. They can also resurface at other transitional times, for instance, when a child reaches a milestone. A mother's initial excitement and joy at the sight of her five year old child walking may be tempered by her observation of her sister's five year old child beginning to read. At this moment her joy may be mixed with a resurfacing of disappointment and sadness. A father who has just witnessed his six year old throw a ball with good aim may be saddened when observing other six year olds march in the Memorial Day parade with their Little League teams.

Not all feelings are negative, however, and many families share stories of courage, personal growth, happiness, and joy when they discuss their children with disabilities and special health care needs. They point out how the family has emerged stronger, closer, and wiser; more accepting and tolerant of differences. Parents point with pride to their other children who have learned to celebrate diversity. The mother of an infant with Down Syndrome rejoices as her child survives major heart surgery that had threatened to end her life. The parent of the honor student beams as his son sits with a peer who is a wheelchair user in the cafeteria.

All families go through adjustment and adaptation periods with the addition and growth of their members. Families of children with disabilities and special health care needs experience these challenges in different ways. Each family finds its own way of adjusting to the change in lifestyle required by the child with extraordinary needs and gifts. However, the typical periods of adjustment may be more difficult, often involving significant changes or, at times, crises. This may lead to an increase in the normal stresses associated with parenting. Most families adjust well to these changes and continue to grow as unique family systems. However, some families may feel overwhelmed at particular times. They may need additional assistance to increase their capacity to use their unique skills and resources in coping with change.

Protective factors which promote comfortable adjustments include the availability of support systems chosen by the family. These may include formal systems (professionals, therapists, doctors) and informal systems (neighborhood groups, parent-to-parent support, churches, friends, family, community service groups); as well as access to economic resources, information networks, and recreational opportunities.

In order to understand why families vary so dramatically in their responses to having a child with a disability, it is important to understand how resilience, vulnerability, and risk factors can influence the probability of potential problems. For instance, if a family's vulnerability is high (living in poverty, no health insurance, history of alcoholism), and the risk factor is high (conflicts with extended family members, poor community resources), then the probability for a problem to occur is high. Preventative interventions for families should be designed to: 1) reduce vulnerability or increase resistance to stressors and 2) decrease environmental risks or add protective factors from outside the family system. Knowing about vulnerability and risk can help service providers to avoid common, unjustified assumptions about certain kinds of families and their resilience.

FATHER AND CHILD INTERACTIONS

Fathers have a tremendous influence on a child's development, particularly in the areas of cognitive, personal and social development, and the development of gender identity. When fathers interact with their children, it is most often spent in play activities. Fathers may not directly be involved in the health care issues concerning their typically developing children. This may be even more true for children who have developmental delays or special health care needs.

Because of work schedules and the lack of flexible work hours for many fathers, the tasks of managing educational and health care systems are delegated to the mother. As a result, pediatricians have more direct contact with the mother of a child with a disability than with the father. This is also true for other service providers, including home health aides, nurses, therapists and teachers. Fathers must often rely on second hand information provided by the mothers. It is easy to overlook the roles of fathers and their importance in enhancing the overall quality of life for children with disabilities and chronic health care needs.

Fathers may have little direct contact with the physician and other service providers, they may at times feel left out and lacking in the necessary expertise to promote a comfortable relationship with their children. The reluctance some fathers appear to have is often attributed to "distancing " or a "lack of bonding" by professionals, when in reality it may be the result of the way medical and educational systems interpret the actions of fathers. A father, who appears to be uncomfortable holding his small, crying child diagnosed with cerebral palsy, may be uncomfortable for a number of reasons. He may not be used to small babies or have difficulty understanding why the baby is crying. He may not know how to hold his infant, or how to provide security or comfort to the infant.

Professionals need to be cautious in interpreting a father's lack of motivation to engage with the child or participate in an intervention activity. Open communication between the father, the pediatrician, and other professionals may elicit more information from the father. For fathers, an indication from the service provider that their input and participation is desired can provide the invitation needed for them to become more active participants.

The priorities and preferences of fathers should be considered as part of any intervention program. Too often, service delivery is scheduled around the mother's daily routines without attempting to include the father. Time preferences, availability, and parenting styles should be solicited from the father, as well as the mother, in planning and implementing service delivery. Fathers tend to prefer verbal interaction, physical involvement, and games requiring problem solving when playing with their young children. Fathers should be provided opportunities to learn about the ways young children communicate, and supported in their interactions with their children.

SIBLING INTERACTIONS

Perhaps one of the longest bonds that a person will develop is with a sibling. Sibling interactions affect the entire family, and family decisions concerning the child with a disability can affect sibling relationships. There are many factors that can influence the sibling relationship, for example, age, family characteristics, type of disability, and characteristics of the siblings without disabilities. Depending upon these and other factors, the reactions and behaviors of the siblings will vary.

A child's adjustment to a sibling with a chronic health care need or disability depends upon a variety of economic, personal, emotional, and social factors. Among them are several of the following:

- Nature and severity of the sibling's disability
- Parents' feelings and reaction to the child with a disability
- Availability of both formal and informal support systems
- Age span between children
- Age of the child with a disability
- Extent that the child's disability impacts the home environment and family functioning
- Amount and type of responsibility placed on the other children
- Financial status of the family
- Ready access to services
- Size of the family

Siblings experience both positive and negative feelings and concerns about having a brother or sister with a disability. These feelings may involve self perceptions, perceptions of the child with the disability, their relationship to their parents, and their interactions in the community. Some of the most common feelings are highlighted below:

Positive feelings:

- Pride in the accomplishments of their sibling
- Appreciation for their intelligence
- Closer, warmer relationships with their parents
- Pride in their ability to help

- Compassion
- Enhanced sense of responsibility
- Acceptance of diversity in others
- Appreciation of their own good health
- Maturity
- Patience
- Increased protection of the sibling
- Awareness of the needs of others

Difficult feelings:

- Misunderstandings about the disability
- Jealousy of differential treatment by parents
- Anger at the demands the child places on the family and its resources
- Embarrassment
- Resentment when rules and expectations differ
- Fear of the disability and the way others perceive it
- Isolation/loneliness from peers, school, community
- Guilt at their good fortune

Siblings need opportunities to talk about and share their feelings. They need to be listened to and respected. Their opinions should be willingly solicited and accepted. They need honest, direct and understandable information across the lifespan of their sibling; as well as education and training in dealing with the specific challenges of the disability. Suggestions that help parents support their children include providing information, accepting feelings, helping the develop strategies for balancing responsibilities, and enhancing their own sense of competence.

Siblings of a child with disabilities may need support for any of the following questions or concerns that may be expressed:

With their friends:

- How to tell them
- How to handle their own negative feelings

- How to make them understand
- How to handle taunting and teasing
- How to gain acceptance for themselves and their sibling

In the community:

- What to say when people stare
- How to help their sibling behave
- How to help their parents in public
- What to do if the sibling embarrasses them
- Responsibility for their sibling at school
- Responsibility for their sibling in community places (parks, schools, stores)

In adulthood:

- Their own genetic make-up
- Acceptance by a spouse/spouse's family
- Continued emotional, social medical and financial responsibility for their sibling
- Community acceptance
- Starting a family

LIFESPAN ISSUES

All families face lifespan issues, which may present challenges, including families of children with disabilities or special health care needs. However, families whose children have disabilities or special health care needs often face unique challenges, based on the individual strengths and needs of their children. Physicians who are aware of these issues can play an important role in acknowledging them and providing information and guidelines about issues which may inevitably arise.

It is important for the physician to be aware of lifespan issues and ways in which they can be addressed. It is especially important to adapt information to meet the changing needs of the individual and family. In addition, just as it is essential that the physician understand how families are impacted by having a child with a disability or special health care need, it important to consider how our society as a whole perceives and treats individuals with disabilities. The pediatrician treating the child with a disability must focus on the physical needs of the child, and also on the emotional and social issues associated with being disabled in our society.

There are points in the lives of families that present opportunities for children to transition into new levels of awareness and learning with concurrent increases in responsibility and independence. These natural transition times may vary for families with children who have disabilities or special health care needs. They may also present significant logistical, emotional, social, and financial challenges to such families. These transition times can include initiating the child into formal school programs (kindergarten, middle school, high school, college, or the working world). Transitions require adjustments not only on the part of the child, but also on the part of the parents.

Transitions are not the only lifespan challenge that parents of children with disabilities and special health care needs face. In addition, these families experience "off time transitions" and "the prolongation of parenting stages" that other families move through more quickly. Thus, the mother of a physically and cognitively challenged individual may find herself providing basic personal care to her child when she is fifty years old, well past the time other parents have attended to these needs.

An overview of some of the lifespan issues faced by families with children with disabilities or special health care needs include:

- **Childhood:** From the time that a child is diagnosed with a disability or special health care need the family must cope with the impact the diagnosis will have on their lives as a family. The family will have to deal with changes in almost every aspect of what they might have thought would be the normal social progression of the child's life. What might have been a time for settling into parenthood, may turn into a time of developing coping strategies, lifestyle adaptations, and redefining of family roles. The pediatrician for the family whose child has a disability can better help the family through difficult situations by being sensitive to family dynamics and being knowledgeable about sources of support.

  Many parents express a need for guidance and suggestions from the pediatrician early on in the child's life. They may be especially interested in learning about methods for addressing behavioral problems. Middle childhood (ages 5 to 10) seems to be a time for the permanence of the child's disability to become much more evident to the child's family members. Parents have expressed that this is the point during which they shift their focus from basic survival needs to planning for their child's future. They also begin to address issues such as social interactions, friendships, and independence.

- **Adolescence:** The second major transition time for families of children with disabilities occurs during adolescence. The onset of puberty often raises serious concerns and fears for the caregiver. It is important not to assume that just because a child has a disability, that he or she will not encounter such milestone issues as sexual desire, concerns about peer relations, or learning to drive a car. Adolescents with disabilities often are overlooked in their right to learn to do things that everyone else does. Issues such as dating, menstruation, sexual activity, and other adolescent concerns need to be addressed sensitively with the family and the adolescent. The pediatrician may be called to mediate or explain such issues to those involved.

- **Adulthood:** Lifespan issues such as parent illness, reproduction, and vocation are part of the lives of persons with disabilities. Because of the increased dependence of a child with a disability on the parent/caregiver, issues such as parent illness and parent death are of paramount importance. As the pediatrician, it is important to begin fostering the personal independence of children with a disability early in their childhood. Pediatricians can assist families in learning about ways in which they can facilitate their children's independence by providing information about adult issues well before their onset and encouraging parents to foster independence during childhood and adolescence.

MEDICAL HOME MODEL

A lifetime of intensive, supportive health care is often necessary for a child with special health care needs. Multiple specialty providers, innumerable hospitalizations, and changes of service providers often leave both families and providers confused about who is responsible for coordinating care. This confusion may lead to poor or inadequate information sharing among the many individuals serving the family. To avoid this, parents often assume the role of updating medical information for everyone involved with the child. This frustrating task of coordinating ever-changing information among specialists, combined with the difficulty of meeting the financial demands, poor availability of qualified, competent child care, and coping with the high degree of responsibility in the daily care for a child with chronic health care needs, creates enormous stress for the family.

To help alleviate some of the family's stress, children with special health care needs should be cared for within the context of a medical home. A medical home is an approach to providing health care services in a high-quality and cost effective manner. It is not a building, house or hospital. The ideal source of a child's medical home is a primary health care provider (defined as a pediatrician, hospital clinic resident, nurse practitioner, specialty pediatrician, family practitioner, or specialist) working in partnership with the child's parents. Together, they identify and access all of the medical and non-medical services needed to help children and their families achieve their maximum potential.

The American Academy of Pediatrics (AAP) presents the medical home concept as a way of delivering accessible, continuous, comprehensive, family centered, coordinated, and compassionate medical services to children.

SERVICES WITHIN THE MEDICAL HOME

The medical home model promotes opportunities for effective collaboration among physicians, other health care providers, and the community and educational agencies involved in providing services to children with disabilities and special health care needs and their families. The ideal medical home encompasses the following services:

- Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, healthcare supervision, anticipatory guidance, and patient and parental counseling about health and psychosocial issues.
- Assurance of ambulatory and inpatient care for acute illnesses, twenty-four hours a day, seven days a week, during the work day, after hours, on weekends, fifty-two weeks a year.
- Provision of care over an extended period of time to enhance continuity.
- Identification of the need for subspecialty consultation and referrals, and knowing from whom and where these can be obtained; provision of medical information about the patient to the consultant; evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
- Interaction with school and community agencies to be certain that the special health needs of the individual child are addressed.

- Maintenance of central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, while maintaining confidentiality.

The AAP Medical Home Program for Children with Special Needs also provides support to physicians to enhance their health care practices for children with disabilities or special health care needs. This program provides information about strategies and educational materials, as well as technical assistance to physicians, for developing a medical home program within their practice. For more information about support for physicians using the medical home model contact:

Elizabeth Osterhus
AAP Department of Community Pediatrics
1-800-433-9016, ext. 7621

BENEFITS OF THE MEDICAL HOME

The medical home creates a partnership between the family and the child's primary health care provider, encouraging collaborative decision making, continuity of care, and family support in times of need. The medical home model provides many benefits to children and families, as well as to health care and other service providers. These benefits are described below:

- **Continuity of care:** A child with special health care needs often has medical problems that may develop suddenly and require the expertise of a pediatric primary health care provider who is familiar with the child's history. The medical home guarantees the availability of medical support around the clock. This assurance of appropriate medical care, by a health care provider who knows the child's history, provides great comfort for the family.

- **Effective communication:** The multiplicity of specialists and providers for the child with special health care needs presents many challenges to the family. In the medical home model, a family has one primary contact for the child. The medical home encourages effective communication among specialists and the primary health care provider. This accessibility to the child's medical information relieves the burden on the family for understanding and disseminating information about technical procedures, treatment protocols, and new findings to the various specialists caring for the child.

- **Family Centered Care:** Family Centered Care supports families as the center of the decision making process. This value is also the foundation of the medical home model. Collaboration among families, primary health care providers, medical specialists, and the staff of the medical offices creates problem solving partnerships and strengthens the sources of support for families and their children with special health care needs. A medical home encourages this partnership by defining a common goal and vision. A relationship is often formed between the family and a member of the medical provider's office staff (i.e., a nurse or physician assistant). This staff person becomes an important contact for the family and gains an understanding of the family's expertise and insight. This type of relationship makes access to the physician's office easier for the family.

- **Appropriate documentation:** Frequent regulation and monitoring of medications, treatments, and assistive devices are quite commonplace for families whose children have special health care needs. Often, medical interventions must be changed or modified to achieve an optimal level of care. Additionally, medical supply companies, public assistance programs, and insurance providers require documented approval of medications, medical supplies, assistive technology, and nutritional supports as modifications occur. The medical home model minimizes the frustrating red tape that can overwhelm families as they deal with confusing funding issues. The medical home provides a family with a primary health care provider and support staff, who are easily accessible and able to provide this documentation in a timely manner.

- **Record keeping:** The medical home model maintains an accessible, confidential medical record that merges all specialties and integrates them into one comprehensive resource. If it is necessary for the child to be referred to another medical center or if the child needs to be hospitalized, this complete and concise medical record can readily provide a wealth of medical information and recommendations.

The medical home concept emphasizes that the primary health care provider acts as the coordinator of all aspects of pediatric care, and supports the child and family as they attempt to address the health care needs in the school and community settings. The medical home model provides the necessary supports to ensure that these children get the care and educational opportunities they deserve. Through the establishment of the medical home, families can more confidently address the educational and medical needs of their children.

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THE FAMILY CENTER AT CONNECTICUT CHILDREN'S MEDICAL CENTER

The Family Center at Connecticut Children's Medical Center, Hartford, Connecticut is housed in the Center for Children with Special Health Care Needs (CSHCN), under the management of Ambulatory and Community Services. The purpose of the Family Center is to provide support to parents so that they may better meet their child's special health care needs. Families who have a child with a disability are faced with a multitude of agencies, service providers, case managers, funding sources and specialty medical care. Each of these services focuses on a different aspect of the child's needs, creating a difficult to access and highly fragmented system of care for children with disabilities.

Although families of children with disabilities may have many service providers, they may still identify many unmet needs such as: assistance about learning the resources that are available to them; improving their own abilities to negotiate on behalf of their child; understanding the laws and regulations governing these services; and increasing their general knowledge about their child's disability. In addition to these needs, parents may feel isolated, alone, and stressed in meeting the daily care needs of their child.

The Family Center assists families through the following activities:

- Support, information, and training on a one to one basis for families, both at the hospital and in the community.
- Technical assistance on resources and services for children with disabilities or special health care needs and their families.

- Direct advocacy, particularly in issues of health care financing, including fair hearings for Medicaid and Social Security.
- Parent-to-parent support, through the establishment of a statewide network of 13 Parent-to-Parent chapters.
- Self advocacy training provided through both formal and informal training programs.

The Family Center also provides support and training to professionals who work with and care for children with disabilities and their families. The Center is unique in its approach to family support in that all of the operations have remained entirely family directed and all programs are staffed by parents of children with disabilities. Services are provided at no cost to families. To contact:

The Family Center
Connecticut Children's Medical Center
282 Washington Street
Hartford, CT 06106
(860) 545-9023

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FAMILY STUDY -- REVISITED

DISCUSSION QUESTIONS

As JP's primary pediatrician, evaluate the following:

What do you see when you look at this family?

What staff member and/or health care professional should explore the issues affecting Pilar's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

What should be included in JP's discharge plan?

How will you ensure JP's discharge plan is being implemented?

How might your own cultural beliefs, values, and customs, influence your behavior and thus your interactions with JP, his family, and other professionals?

How can you effectively communicate with individuals of different cultures?

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DISCUSSION QUESTION ANSWERS

- What do you see when you look at this family?
  - Does your description include the following family strengths and resources?

    a) Pilar loves JP.

    b) Pilar's strong determination to provide care for JP at home.

    c) Pilar took time off from work to participate in the planning process for JP's discharge.

    d) Pilar visited JP despite transportation difficulty.

    e) Pilar has some friends for emotional support.

    f) Pilar has kept her job throughout the stress and trauma of JP's hospitalization.

    g) Pilar's customs and beliefs may differ from the teams'.

  - Does your description include the family needs and concerns such as, insurance benefits, child care and transportation? Other family needs and concerns include, assistance in coordinating JP's doctor's appointments, support for Pilar to help her understand JP's needs, employment counseling for Pilar, the language barrier, and securing a telephone.

- What staff member and/or health care professional should explore the issues affecting Pilar's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

- Pilar, JP's pediatrician, primary care nurse, discharge planner (nursing), and social worker should be involved in identifying the issues affecting Pilar's ability to visit JP in the hospital and participate in his care. The early intervention service coordinator should be involved if a referral to Birth to Three takes place prior to discharge.
- These issues should be addressed in a team meeting of the above individuals in a collaborative, family centered manner. They should all work toward the goal of JP being cared for at home with his mother.
- The family's role should be as an equal team member in the discharge planning.

❖ What should be included in JP's discharge plan?

- Referral to a visiting nurse.
- Medical equipment from a home health supply vendor.
- Medication for seizures.
- Referral to Birth to Three, early intervention services.
- Referrals for medical follow-up appointments.
- How the discharge planning team feels the following issues should be addressed: Pilar's need for a telephone; health care financing; transportation; Pilar's ability to get JP to multiple appointments without losing her job; Pilar's support needs; and child care.

- How will you ensure JP's discharge plan is being implemented?
  - Maintain regular communication with the family, other health care providers, and the child's service coordinator, if referred to early intervention services.

- How might your own cultural beliefs, values, and customs, influence your behavior and thus your interactions with JP, his family, and other professionals?
  - The answer will be different for each physician.

- How can you effectively communicate with individuals of different cultures?
  - Understand and appreciate one's own culture.
  - Understand and appreciate other individual's cultural identity.
  - Seek out information specific to individual cultures, focusing on the cultures of the families you work with, including styles of interaction, communication, and values.
  - Recognize and continuously develop your own interpersonal skills when interacting with people.
  - Recognize that not all people of one cultural background are the same.
  - Respect the individuals from a different culture.
  - Make continual efforts to understand the issues and situation from the family's point of view.
  - Be open to new approaches and learning that people of different cultures may bring your way.

- Be flexible.
- Have a sense of humor.
- Tolerate uncertainty and seek clarification.

RESOLUTION

Pilar was committed to caring for JP at home. Despite limitations in transportation, she did manage to visit JP and was very nurturing towards him, spending hours in the hospital rocking and hugging him. Prior to his discharge, she learned how to care for JP, including how to operate all of his medical equipment. Pilar had a few friends who provided her with emotional support. She had managed to keep her job despite the stress and trauma of JP's hospitalization, and was struggling to meet both of their needs.

Using a family centered model, the following people began discharge planning for JP after the sixth week of his hospitalization, when his health stabilized:

- Pilar
- Primary NICU physician
- Primary nurse
- Discharge planner (nursing)
- Social worker (hospital based)
- Visiting nurse (community based)
- Community pediatrician
- Translator

The discharge planning included three team meetings: at 8 weeks, 16 weeks, and just prior to discharge. Pilar was able to attend only one of these meetings, but met with JP's primary nurse before and after each meeting to discuss the plans and her own concerns. Pilar also met with the hospital social worker on four other occasions. The visiting nurse made one visit to

Pilar's home before discharge and assessed JP's home care needs. During the discharge planning process, Pilar identified several of her concerns, including a lack of insurance benefits. She would need to find child care for JP, and expected that this would be difficult because of his medical and developmental needs. She did not have a car of her own and worried about being able to return for medical appointments with JP. She was also concerned about taking too much time off from work. She also had questions about JP's long-term care needs and prognosis. She felt that she had no one to support her and assist her in understanding these issues.

With Pilar's input relayed by the primary nurse, the team wrote the discharge plan at their last meeting. Afterwards, the nurse met with Pilar to explain the plan. A referral for early intervention was discussed with Pilar and she said she would think about it. Her copy of their discharge summary included telephone numbers and appointments, and information on the following medical needs:

- The medical equipment needed and the home-health supply vendor phone number.
- Proper dosages and administration of medications for seizures.
- Referral to early intervention services for developmental follow-up and physical therapy.
- Referrals for follow-up in the following specialties: ophthalmology, neurology, pulmonary, audiology, and developmental follow-up clinic.
- Referral for eight hours of home nursing per day.

In addition to JP's medical/developmental needs, Pilar's other concerns were addressed through the discharge plan:

- Pilar's need for a telephone. The hospital social worker secured a donation from a local charitable foundation to have a phone installed; Pilar understood that ongoing bills would be her responsibility.
- Health care financing. Pilar was assisted in applying for Medicaid (Title XIX) and WIC (food supplement for pregnant women, infants and children). At the time of JP's discharge, she had met the eligibility requirements: JP's care, as well as her own, was covered.
- Transportation. Medicaid would pay for transportation to medical appointments.
- Multiple care providers and appointments. The visiting nurse agreed to act as a service coordinator, and would assist Pilar in coordinating appointments on the same day.
- Support needs for Pilar. Prior to JP's discharge, Pilar was offered support through Parent-to-Parent, a network of trained veteran parents who have children with disabilities. She was matched up with another mother who visited her several times at the hospital, and they planned to continue meeting after discharge. The discharge plan also contained a referral to an employment counseling agency which would help Pilar find permanent work.
- Child care needs for JP. JP would receive eight hours a day of home nursing while Pilar was working; this coverage would continue as long as JP needed skilled care. Should his condition improve, Pilar would again need to find child care. The Visiting Nurse Association would assist her in training a child care provider, but Pilar was aware that this care may be costly and difficult to secure.

With the appropriate support, including a good relationship with JP's primary care pediatrician, Pilar and JP can eliminate barriers to implementing a successful discharge plan and effectively deal with the challenges they face in the future.

SATISFACTION WITH SESSION PRESENTATION: FAMILY CENTERED CARE

Resident's Name:____________________

Date of Visit:____________________

Please respond to the following statements by circling your response on a scale from 1 to 5:

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

	The Facilitators:	Strongly Disagree	⟷			Strongly Agree
1.	Were prepared for the session.	1	2	3	4	5
2.	Were organized.	1	2	3	4	5
3.	Stated clear objectives.	1	2	3	4	5
4.	Were articulate/spoke clearly.	1	2	3	4	5
5.	Allowed enough time for questions.	1	2	3	4	5
6.	Sufficiently answered questions.	1	2	3	4	5
7.	Valued my input.	1	2	3	4	5
	The Content:					
8.	Objectives of the session were met.	1	2	3	4	5
9.	The session provided me with a clear understanding of Family Centered Care.	1	2	3	4	5
10.	Overall rating of the session.	1	2	3	4	5

11. What, if anything, would you like to see added to or omitted from the Family Centered Care didactic session?

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Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: FAMILY CENTERED CARE DIDACTIC SESSION

Resident's Name:____________________

Preceptor's Name:____________________

Date of Session:____________________

The Resident:

1. Demonstrated appropriate professional behavior. ☐ Yes ☐ No

2. Actively listened. ☐ Yes ☐ No

3. Avoided the use of jargon or medical terms, or explained them. ☐ Yes ☐ No

4. Generally participated in the discussion. ☐ Yes ☐ No

5. Asked appropriate questions. ☐ Yes ☐ No

6. Did the resident arrive/depart at the scheduled time? ☐ Yes ☐ No
If no, please explain.

The Session:

7. Was there more than one resident? ☐ Yes ☐ No
If yes, how many?

8. If there was more than one resident, did this enhance the session? ☐ Yes ☐ No
Please explain.

9. Was the resident post-call? ☐ Yes ☐ No

10. Was a person representing the family perspective present? ☐ Yes ☐ No
If yes, please list who, along with any other staff present.

11. Did the resident make suggestions to enhance future didactic sessions? If yes, please list. ☐ Yes ☐ No

12. Were there any difficulties with the session? ☐ Yes ☐ No

13. Did you have any outstanding experiences with this session? ☐ Yes ☐ No

COMPONENTS TWO AND THREE: HOME VISITS WITH TWO FAMILIES

Location and Times:

You will meet with two families of children with disabilities or special health care needs in the family's home.

We will attempt to schedule visits according to the block schedule, however, in some cases it may be necessary to meet with families during evening hours or on the weekend. This will be arranged between you and the family.

Format:

The goal of the visits is to find out how having a child with special needs has impacted the family and their perceptions of the health care system, etc. Please refer to *Guidelines for the Home Visit.*

Resident's Responsibilities:

- **First home visit**: You will be assigned a family that is participating in this project by the Project Coordinator. The Project Coordinator will contact the family and arrange the home visit.
  - The *Resident Self Evaluation of First Home Visit* should be completed and returned to the Division of Child and Family Studies. The *Performance Rating by Preceptor* form should be

completed by a family member and returned to the Division of Child and Family Studies.

- **Second home** visit: You should identify a child from your continuity clinic for the home visit. Please refer to *Guidelines for Identifying Children with Disabilities and Special Health Care Needs within the Continuity Rotation* in Appendix A. You should then obtain permission from the parents and arrange the home visit at a mutually agreed upon time.
    - The *Resident Self Evaluation of Second Home Visit* should be completed and returned to the Division of Child and Family Studies. If you are accompanied by project staff to the home visit, *Performance Rating by Preceptor: Second Home Visit* should be completed by project staff. If the resident attends the visit alone, the form should be completed by a family member.

COMPONENTS TWO AND THREE: GUIDELINES FOR HOME VISITS

Purpose:

- To gain an increased understanding of a child within his or her home environment, including the family's strengths, concerns, priorities, and resources as they relate to the child's disability or special health care needs.

Family Interview- Suggested Outline:

- Identify the positive experiences the family members have had in their home, community, school or child care program(s), and with the health care system.
    - What factors have contributed to making these experiences positive?

- Identify challenges the family members have experienced in their home, community, school or child care program(s), and with the health care system.
    - What factors have contributed to these challenges?
    - How might these issues be addressed?
    - What role could the physician play in addressing these issues?

- Identify the family's current concerns and needs with regard to the home environment, school or child care program(s), and health care system.
    - What are this family's major concerns, priorities, and resources?
    - What supports might be offered to this family?
    - How are extended family members involved with this child?
    - How do siblings interact with the child? What are the positive aspects? Challenges?
    - How are friends and neighbors involved with this family?

- Discuss the components of the child's current school or child care program.
    - Is the child receiving early intervention or special education services?
    - Is the child included in a class or other setting with children who do not have disabilities, a mainstream or inclusive environment? Describe the process in place for successful inclusion.
    - Does the child receive related services such as occupational therapy, physical therapy, speech and language therapy, and counseling? Where are these services provided? How?
    - Does the child use any assistive technology at school, such as a computer, an assistive language device, a modified spoon, or Velcro on a writing tool?
    - Who is responsible for implementing technology? How is this accomplished?

- How do the child's health care needs impact his or her ability to participate in the program?

RESIDENT SELF EVALUATION: HOME VISIT

Resident's Name:__________________________

Date of Visit:______________________________

Child's Initials:_______________________________ Age:____________ Gender:______________

1. Does this family feel that the care they have received from professionals has met their needs and has been family centered? If yes, how has it been family centered? If no, why not and how can this be changed?

2. Has this family found the health care system to be flexible, accessible, and responsive to their needs? Please give an example.

3. What supports and services has the family found most useful?

4. Does this family have a collaborative relationship with their pediatrician? (If the pediatrician is someone other than the resident.)

   a) If yes, how does this benefit them?

   b) If no, how could one benefit them?

5. Does this child have a medical home? If yes, which practitioner facilitates the medical home model? Please give an example of services provided by the medical home. If no, how could one benefit them?

6. Are there activities that the family would like to do but feel they cannot because of the child's disability? Please give an example.

7. Did you gain a sense of the positive aspects of this child's life from the family's perspective? ☐ Yes ☐ No

8. Did this visit enhance your understanding of how the family is the constant in the child's life? ☐ Yes ☐ No

9. Did you gain a sense of the parents' concerns and priorities regarding their child? ☐ Yes ☐ No

10. Did you gain a sense of the strengths of this child and this family? ☐ Yes ☐ No

11. Did you gain more awareness of family systems issues including milestones, transitions, and lifespan issues? ☐ Yes ☐ No

12. Do you understand more about this family's culture, beliefs, and values as they relate to this child's family and community? ☐ Yes ☐ No

13. Do you understand more about this family's culture, beliefs, and values as they relate to health care and health care practices used by this family? ☐ Yes ☐ No

14. Did you gain a sense of what these parents want from a pediatrician? ☐ Yes ☐ No

15. Were you satisfied with the preparation given for this experience during the Family Centered Care didactic session? ☐ Yes ☐ No

16. Was this visit beneficial to you as a physician? ☐ Yes ☐ No

17. Were you satisfied with the experience and knowledge gained from this visit? ☐ Yes ☐ No

18. What might you do differently in your practice as a result of this experience?

19. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please describe.

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in the home visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: HOME VISIT

Family Member's Name:________________

Resident's Name:________________

Date of Visit:________________

The Resident:

1. Appeared to appreciate our strengths as a family. ☐ Yes ☐ No
2. Asked about our support systems and resources. ☐ Yes ☐ No
3. Encouraged us to share our priorities and concerns about:
    - a) school ☐ Yes ☐ No
    - b) community life ☐ Yes ☐ No
    - c) medical and health issues ☐ Yes ☐ No
    - d) professionals ☐ Yes ☐ No
4. Was interested in understanding all aspects of our child's life. ☐ Yes ☐ No
5. Demonstrated respect for our family's beliefs, values, culture, and customs? ☐ Yes ☐ No
6. Demonstrated appropriate professional behavior. ☐ Yes ☐ No
7. Actively listened. ☐ Yes ☐ No
8. Communicated clearly. ☐ Yes ☐ No
9. Appeared comfortable with our child and family. ☐ Yes ☐ No
10. Asked questions when he/she was confused. ☐ Yes ☐ No

11. Appeared well prepared for this visit. ☐ Yes ☐ No

12. Did the resident spend an adequate amount of time with your family? ☐ Yes ☐ No

13. Overall, were you satisfied with this experience? ☐ Yes ☐ No

14. Would you be willing to host another resident? ☐ Yes ☐ No

15. Did you have any difficulties during this experience? If yes, please describe. ☐ Yes ☐ No

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in this resident visit and your honest feedback.

RESIDENT SELF EVALUATION: HOME VISIT

Resident's Name:____________________

Date of Visit:____________________

Child's Initials:____________________ Age:________ Gender: ________

1. Does this family feel that the care they have received from professionals has met their needs and has been family centered? If yes, how has it been family centered? If no, why not and how can this be changed?

2. Has this family found the health care system to be flexible, accessible, and responsive to their needs? Please give an example.

3. What supports and services has the family found most useful?

4. Does this family have a collaborative relationship with their pediatrician? (If the pediatrician is someone other than the resident.)

    a) If yes, how does this benefit them?

    b) If no, how could one benefit them?

5. Does this child have a medical home? If yes, which practitioner facilitates the medical home model? Please give an example of services provided by the medical home. If no, how could one benefit them?

6. Are there activities that the family would like to do but feel they cannot because of the child's disability? Please give an example.

7. Did you gain a sense of the positive aspects of this child's life from the family's perspective? ☐ Yes ☐ No

8. Did this visit enhance your understanding of how the family is the constant in the child's life? ☐ Yes ☐ No

9. Did you gain a sense of the parents' concerns and priorities regarding their child? ☐ Yes ☐ No

10. Did you gain a sense of the strengths of this child and this family? ☐ Yes ☐ No

11. Did you gain more awareness of family systems issues including milestones, transitions, and lifespan issues? ☐ Yes ☐ No

12. Do you understand more about this family's culture, beliefs, and values as they relate to this child's home and community life? ☐ Yes ☐ No

13. Do you understand more about this family's culture, beliefs, and values as they relate to health care and health care practices used by this family? ☐ Yes ☐ No

14. Did you gain a sense of what these parents want from a pediatrician? ☐ Yes ☐ No

15. Were you satisfied with the preparation given for this experience during the Family Centered Care didactic session? ☐ Yes ☐ No

16. Was this visit beneficial to you as a physician? ☐ Yes ☐ No

17. Were you satisfied with the experience and knowledge gained from this visit? ☐ Yes ☐ No

18. What might you do differently in your practice as a result of this experience?

19. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please describe.

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in the home visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: HOME VISIT

Family Member's Name:____________________

Resident's Name:____________________

Date of Visit:____________________

The Resident:

1. Appeared to appreciate our strengths as a family. ☐ Yes ☐ No
2. Asked about our support systems and resources. ☐ Yes ☐ No
3. Encouraged us to share our priorities and concerns about:
    - a) school ☐ Yes ☐ No
    - b) community life ☐ Yes ☐ No
    - c) medical and health issues ☐ Yes ☐ No
    - d) professionals ☐ Yes ☐ No
4. Was interested in understanding all aspects of our child's life. ☐ Yes ☐ No
5. Demonstrated respect for our family's beliefs, values, culture, and customs? ☐ Yes ☐ No
6. Demonstrated appropriate professional behavior. ☐ Yes ☐ No
7. Actively listened. ☐ Yes ☐ No
8. Communicated clearly. ☐ Yes ☐ No
9. Appeared comfortable with our child and family. ☐ Yes ☐ No
10. Asked questions when he/she was confused. ☐ Yes ☐ No

11. Appeared well prepared for this visit. ☐ Yes ☐ No

12. Did the resident spend an adequate amount of time with your family? ☐ Yes ☐ No

13. Overall, were you satisfied with this experience? ☐ Yes ☐ No

14. Would you be willing to host another resident? ☐ Yes ☐ No

15. Did you have any difficulties during this experience? If yes, please describe. ☐ Yes ☐ No

Additional Comments:

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Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in this resident visit and your honest feedback.

COMPONENT FOUR: SPECIALTY CLINIC VISIT

Location and Times:

You will be scheduled to attend a specialty clinic for one half day based on your interests and schedule.

Format:

There are two formats for specialty clinic visits:

- Accompany a family you have met through your continuity clinic to a scheduled visit in a specialty clinic (please refer to *Guidelines for Identifying Children with Disabilities or Special Health Care Needs within Continuity Rotation* in Appendix B of the Family Centered Care module).

OR

- Attend a specialty clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time you will interview at least one family. See *Specialty Clinic Experience: Guidelines for Family Interview.*

Resident's Responsibilities:

- Prior to attending the specialty clinic, you should complete some independent reading about the medical issues associated with that disability or condition treated in this clinic.

- During the clinic visit please follow these procedures:
  - Inform the preceptor/family support person that you are there to observe and learn about that specialty from the family/child point of view as part of the Children with Disabilities experience.
  - Be introduced (by the preceptor or family support person) to one or two families that you will follow during the half-day experience.
  - Follow at least one family throughout its entire appointment. For example, you should stay with the family as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
  - Observe and interact with the family (see *Specialty Clinic Experience: Guidelines for Family Interview*).
  - Participate in a debriefing session with the preceptor, family support person, or specialty clinic team.
  - Complete the *Resident Self Evaluation of the Specialty Clinic Visit.*
  - Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

COMPONENT FOUR: SPECIALTY CLINIC VISIT GUIDELINES FOR FAMILY INTERVIEW

Purpose:

- To gain a better understanding of how to provide care for children with disabilities and special health care needs, including: recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.
- To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school and community.
- To gain an in-depth awareness of how clinic visits are viewed through the eyes of the child and family.

Family Interview - Suggested Outline:

- Find out about the family composition, including who lives in the home, where they live, language spoken at home, sources of income, etc.
  - What is a typical day/week like for this child and family?

- Identify the family's perceptions of the child's needs with regard to the home environment, school or child care program, and healthcare system.
- Does the family feel that these needs are being adequately addressed?
- What types of changes can be made, if any?
- If appropriate, ask for the child's input about this clinic visit. What are his or her concerns, questions, priorities, things he likes about coming, dislikes, feelings, etc.?
- What types of social supports does the family have?
- How was this child referred to the clinic? Is this an initial visit or follow-up visit?
- How did the family get to the clinic? Is transportation an issue?
- What does the family feel is the purpose of today's appointment?
- What types of questions do the family members have for the medical team?
- How comfortable does the child appear to be? the family?

RESIDENT SELF EVALUATION: SPECIALTY CLINIC VISIT

Resident's Name: ____________________

Date of Visit: ____________________

Contact Person: ____________________

Name of Clinic: ____________________

1. Was this visit an initial or follow-up visit?

2. List two of the family's *strengths* and *resources*:

3. List the family's top *priority* regarding the care of the child:

4. What were some of the family's main *concerns* regarding the care of the child?

   a) Were these the same for everyone on the medical team? ☐ Yes ☐ No

5. Did the medical team demonstrate Family Centered Care practices when working with the family? Explain and give an example.
   (If necessary, review the nine principles of Family Centered Care on page 19 of this module.)

6. Does this child's medical needs affect his or her ability to participate fully in home, school, or community activities? If yes, what adaptations are in place to allow the child to participate?

7. Is this family dealing with any specific lifespan issues? For example, are there any transitions occurring at this time? If yes, explain.

8. Does this child's have a medical home? ☐ Yes ☐ No

   a) If yes, which practitioner facilitates the medical home model?

   b) If no, how can a medical home benefit this family?

9. Did this visit enhance your understanding of the family's perspective of the clinic experience? ☐ Yes ☐ No

10. Did this visit enhance your understanding of the challenges faced by families as they schedule and attend clinic visits? ☐ Yes ☐ No

11. Did this visit enhance your understanding of the process of information sharing and collaboration between the clinical team and the family? ☐ Yes ☐ No

12. Did you see examples of the clinic team working with the family to integrate medical, educational, and social services for this child? ☐ Yes ☐ No

13. Were you satisfied with the preparation given for this clinic experience during the Family Centered Care didactic session? ☐ Yes ☐ No

14. Was this visit beneficial to you as a physician? ☐ Yes ☐ No

15. Were you satisfied with the experience and knowledge gained from this clinic experience? ☐ Yes ☐ No

16. What might you do differently in your practice as a result of this experience?

17. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please describe.

18. Is there anything you would like to see added to or omitted from this experience?

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in the clinic visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: SPECIALTY CLINIC VISIT

Preceptor's Name:____________________

Resident's Name:____________________

Name of Clinic:____________________

Date of Visit:____________________

The Resident:

1.	Gained a sense of the family's resources, priorities, and concerns.	☐ Yes	☐ No
2.	Gained a sense of the importance of collaboration between the medical team and the family.	☐ Yes	☐ No
3.	Demonstrated appropriate professional behavior.	☐ Yes	☐ No
4.	Actively listened.	☐ Yes	☐ No
5.	Communicated clearly.	☐ Yes	☐ No
6.	Avoided using jargon when speaking with the family about the child's health care needs.	☐ Yes	☐ No
7.	Displayed competence when working with the child, family, and/or team.	☐ Yes	☐ No
8.	Appeared well prepared for this clinic visit.	☐ Yes	☐ No
9.	Did the resident arrive/depart at the scheduled time? If no, please explain.	☐ Yes	☐ No
10.	Overall, were you satisfied with this experience?	☐ Yes	☐ No
11.	Were you satisfied with the format of this clinic visit for the Children with Disabilities rotation?	☐ Yes	☐ No

12. Did you have any difficulties during this experience? If yes, please describe. ☐ Yes ☐ No

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in this resident visit and your honest feedback.

SATISFACTION WITH MODULE PRESENTATION: FAMILY CENTERED CARE MODULE

Resident's Name:____________________

Date:____________________

Please respond to the following statements by circling your response on a scale from 1 to 5:

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

For this module, I was satisfied with:	Strongly Disagree ⟷				Strongly Agree
1. Organization of the module.	1	2	3	4	5
2. Opportunities provided for questions and discussion.	1	2	3	4	5
3. Quality of reading materials.	1	2	3	4	5
4. Usefulness of the information.	1	2	3	4	5
5. Usefulness of the home visits.	1	2	3	4	5
6. Usefulness of the clinic experience.	1	2	3	4	5
7. Overall rating of the module.	1	2	3	4	5

8. What were the benefits of this module to you as a pediatrician?

9. Do you have suggestions to improve this module?

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in this resident visit and your honest feedback.

APPENDIX A

Communicating With People With Disabilities:
Acronyms and Abbreviations

FACT SHEET 3

Communicating with People with Disabilities

The Americans with Disabilities Act Fact Sheet Series
October 26, 1992

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Fact Sheets in this series:

Fact Sheet 1. Who Has Obligations Under Title III?
Fact Sheet 2. Providing Effective Communication
Fact Sheet 3. Communicating with People with Disabilities
Fact Sheet 4. Tax Incentives for Improving Accessibility
Fact Sheet 5. Alternatives to Barrier Removal
Fact Sheet 6. Resources for More Information

To obtain additional copies of any fact sheet *in this series, contact your Disability and Business Technical Assistance Center. To be automatically connected to your regional center, call* 1-800-949-4ADA. *This* fact sheet *may be copied as many times as desired by the Disability and Business Technical Assistance Centers for distribution to small businesses but may not be reproduced in whole or in part and sold by any other entity without written permission from the authors.*

Developed under a grant from the National Institute on Disability and Rehabilitation Research (grant #H133D10122).

Adaptive Environments Center, Inc. and Barrier Free Environments, Inc. are authorized by the National Institute on Disability and Rehabilitation Research (NIDRR) to develop information and materials on the Americans with Disabilities Act (ADA). However, you should be aware that NIDRR is not responsible for enforcement of the ADA. The information presented here is intended solely as informal guidance, and is neither a determination of your legal rights or responsibilities under the ADA, nor binding on any agency with enforcement responsibility under the ADA.

FACT SHEET 3

Communicating with People with Disabilities

Employees or customers who have disabilities will feel most comfortable at your place of business if you consider these suggestions for effective communication:

General Considerations

- Do not be afraid to make a mistake when meeting and communicating with someone with a disability. Try following the suggestions below. Imagine how *you* would react if you were in similar situations. Keep in mind that a person who has a disability is a person, and, like you, is entitled to the dignity, consideration, respect, and rights you expect for yourself.
- Treat adults as adults. Address people with disabilities by their first names only when extending the same familiarity to all others present. (Never patronize people by patting them on the head or shoulder.)
- Relax. If you don't know what to do, allow the person who has a disability to put you at ease.
- If you offer assistance and the person declines, do not insist. If it is accepted, ask how you can best help, and follow directions. Do not take over.
- If someone with a disability is accompanied by another individual, address the person with a disability directly rather than speaking through the other person.

"People First" Terminology

- Place the person before the disability. Say "person with a disability" rather than "disabled person."
- Avoid referring to people by the disability they have, i.e., "an epileptic," "blind people." A person is not a condition. Rather, refer to "a person with epilepsy," or "people who are blind."
- People are not "bound" or "confined" to wheelchairs. They use them to increase their mobility and enhance their freedom. It is more accurate to say "wheelchair user" or "person who uses a wheelchair."

Physical Disabilities

- Do not make assumptions about what a person can and cannot do. A person with a physical disability is the best judge of his or her own capabilities.
- Do not push a person's wheelchair or grab the arm of someone walking with difficulty, without first asking if you can be of assistance. Personal space includes a person's wheelchair, crutches, or other mobility aid.
- Never move someone's crutches, walker, cane, or other mobility aid without permission.
- When speaking to a person using a wheelchair for more than a few minutes, try to find a seat for yourself so the two of you are at eye level.

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Produced by Adaptive Environments Center under contract to Barrier Free Environments, NIDRR grant #H133D10122

Visual Disabilities

- Identify yourself when you approach a person who is blind. If a new person approaches, introduce him or her.
- It is appropriate to touch the person's arm lightly when you speak so that he or she knows you are speaking to him or her.
- Face the person and speak directly to him or her. Use a normal tone of voice.
- Don't leave without saying you are leaving.
- If you are offering directions, be as specific as possible, and point out obstacles in the path of travel. Use clock cues ("The door is at 2 o'clock").
- Alert people who are blind or visually impaired to posted information.
- Never pet or otherwise distract a guide dog unless the owner has given you permission.
- You may offer assistance if it seems needed, but if your offer is declined, do not insist. If your offer is accepted, ask the person how you can best help.

Hearing Disabilities

- Ask the person how he or she prefers to communicate.
- If you are speaking through an interpreter, remember that the interpreter may lag a few words behind—especially if there are names or technical terms to be fingerspelled—so pause occasionally to allow him or her time to translate completely and accurately.
- Talk directly to the person who is deaf or hard of hearing, not to the interpreter. However, although it may seem awkward to you, the person who is deaf or hard of hearing will look at the interpreter and may not make eye contact with you during the conversation.
- Before you start to speak, make sure you have the attention of the person you are addressing. A wave, a light touch on the shoulder, or other visual or tactile signals are appropriate ways of getting the person's attention.
- Speak in a clear, expressive manner. Do not over-enunciate or exaggerate words.
- Unless you are specifically requested to do so, do not raise your voice. Speak in a normal tone; do not shout.
- To facilitate speechreading, face into the light, and keep your hands and other objects away from your mouth.
- If the person is speechreading, face the person directly and maintain eye contact. Don't turn your back or walk around while talking. If you look away, the person might assume the conversation is over.
- While you are writing a message for someone who is deaf or hard of hearing, don't talk, since the person cannot read your note and your lips at the same time.
- If you do not understand something that is said, ask the person to repeat it or to write it down. The goal is communication; do not pretend to understand if you do not.
- If you know any sign language, try using it. It may help you communicate, and it will at least demonstrate your interest in communicating and your willingness to try.

Speech Disabilities

- Talk to people with speech disabilities as you would talk to anyone else.
- Be friendly; start up a conversation.
- Be patient; it may take the person a while to answer.
- Give the person your undivided attention.
- Ask the person for help in communicating with him or her. If the person uses a communication device such as a manual or electronic communication board, ask the person how best to use it.

- Speak in your regular tone of voice.
- Tell the person if you do not understand what he or she is trying to say. Ask the person to repeat the message, spell it, tell you in a different way, or write it down.
- To obtain information quickly, ask short questions that require brief answers or a head nod. However, try not to insult the person's intelligence with over-simplification.

Cognitive Disabilities

- Treat adults with cognitive disabilities as adults.
- When speaking to someone who has a cognitive disability, try to be alert to their responses so that you can adjust your method of communication if necessary. For example, some people may benefit from simple, direct sentences or from supplementary visual forms of communication, such as gestures, diagrams, or demonstrations.
- Use language that is concrete rather than abstract. Be specific, without being too simplistic. Using humor is fine, but do not interpret a lack of response as rudeness. Some people may not grasp the meaning of sarcasm or other subtleties of language.
- People with brain injuries may have short-term memory deficits and may repeat themselves or require information to be repeated.
- People with auditory perceptual problems may need to have directions repeated, and may take notes to help them remember directions or the sequence of tasks. They may benefit from watching a task demonstrated.
- People with perceptual or "sensory overload" problems may become disoriented or confused if there is too much to absorb at once. Provide information gradually and clearly. Reduce background noise if possible.
- Repeat information using different wording or a different communication approach if necessary. Allow time for the information to be fully understood.
- Don't pretend to understand if you do not. Ask the person to repeat what was said.
- In conversation, people with mental retardation may respond slowly, so give them time. Be patient, flexible, and supportive.
- Some people who have a cognitive disability may be easily distracted. Try not to interpret distraction as rudeness.
- Do not expect all people to be able to read well. Some people may not read at all.

Please note: This material is based in part on *Achieving Physical and Communication Accessibility*, a publication of the National Center for Access Unlimited, and *Community Access Facts*, an Adaptive Environments Center publication.

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ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ARC	Association for Retarded Citizens
BESB	Board of Education and Services for the Blind
BRS	Bureau of Rehabilitation Services
CPAC	Connecticut Parent Advocacy Center
CA	Chronological Age
CF	Cystic Fibrosis
CP	Cerebral Palsy
CST	Child Study Team
DCF	Department of Children and Families
DMH	Department of Mental Health
DMR	Department of Mental Retardation
DPHAS	Department of Public Health and Addiction Services
ECN	Early Childhood Network
EHA	Education of the Handicapped Act (Public Law 94-142-now called IDEA)
EIP	Early Intervention Project
ESY	Extended School Year
FAPE	Free and Appropriate Public Education
IDEA	Individuals with Disabilities Education Act (1990) (new title for EHA)
IFSP	Individual Family Service Plan
LD	Learning Disability
LEA	Local Education Agency
LRE	Least Restrictive Environment
MA	Mental Age
MD	Muscular Dystrophy
MR	Mental Retardation
MS	Multiple Sclerosis
NBD	Neurobiological Disorders
OT	Occupational Therapy
PDD	Pervasive Developmental Disorder
PL 94-142	Education of Handicapped Act (now IDEA, 1990)
PL 99-457	Education of Handicapped Act, Amendments of 1986 (relates to infants and toddlers)
PPT	Planning and Placement Team
PT	Physical Therapy
RESC	Regional Education Service Center
RFSCC	Regional Family Service Coordination Center
SAT	Student Assistance Team
SCANS	U.S. Secretary's Commission on Achieving Necessary Skills
Sec. 504	Section 504 of the Rehabilitation Act of 1973
SED	Seriously Emotionally Disturbed
SEM	Socially and Emotionally Maladjusted
SERC	Special Education Resource Center
SLP	Speech and Language Pathologist
STC	School to Career
STWO	School-to-Work-Opportunities Act
TBI	Traumatic Brain Injury
TTD/TTY	Teletypewriting Device, Teletypewriter

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dw/[illegible]/acronyms

APPENDIX B

GUIDELINES FOR:

Identifying Children with Disabilities and Special Health Care Needs Within the Continuity Rotation

GUIDELINES FOR IDENTIFYING CHILDREN WITH DISABILITIES 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 to age three) 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
  - Congenital abnormalities

- **Newborn Period:**
  - Failure to thrive
  - Need for medication or medical intervention: e.g., 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
  - Hospitalization or surgeries
  - Neurologic disorders or dysfunctions: seizure disorder, traumatic brain injury

- Recurrent ear infections, cleft palate
- Pulmonary: asthma, cystic fibrosis
- Rehumatology: 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, day care providers, or teachers
  - Attention and concentration
  - Behavioral or emotional difficulties, including reactivity to changes in environment, stress
  - Child abuse
  - Cognitive development/thinking skills
  - Communications 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)

APPENDIX C

REPRINT OF:

American Academy of Pediatrics, Committee on Children with Disabilities (1993). Families' Recommendations for Improving Services for Children With Chronic Conditions. Arch Pediatrics Adolescent Med., 98 (152), 440-448.

APPENDIX D

Forms for Specialty Clinic Visit: Adaptive Equipment Specialty Clinic

SPECIALTY CLINIC VISIT: ADAPTIVE EQUIPMENT

Location and Times:

You will be scheduled to attend the Adaptive Equipment Specialty Clinic for one half day based on the block schedule. Adaptive Equipment Specialty Clinic takes place at Connecticut Children's Medical Center, Rehabilitation Department, on the fifth floor.

Format:

Attend the Adaptive Equipment Specialty Clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time you should use any opportunity to talk with the patients, families, and team members. See *Specialty Clinic Experience: Guidelines for Observation.*

Resident's Responsibilities:

- Prior to attending the Adaptive Equipment Specialty Clinic read the attached summary of medical issues associated with the disabilities or conditions treated in this clinic and any other related readings.

- During the clinic visit follow these procedures:
  - Inform the preceptor/family support person that you are there to observe and learn about the family's/child's point of view as part of the Children with Disabilities Rotation experience.

- Be introduced (by the preceptor) to each family that is attending the clinic on this day.
- Follow the patients throughout their entire appointment. For example, you should stay with the patients as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
- Observe and interact with the patients, family members, and team members. See *Specialty Clinic Experience: Guidelines for Observation.*
- Complete the *Resident Self Evaluation of the Specialty Clinic Visit.*
- Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

SPECIALTY CLINIC EXPERIENCE GUIDELINES FOR OBSERVATION

Purpose:

- To gain an understanding of adaptive equipment needs and concerns for various patients.
- To learn how adaptive equipment needs may impact the patient and his or her family in terms of their ability to participate in typical routines within the home, school, and community.
- To gain an in-depth awareness of how clinic visits are viewed through the eyes of patients and family members.

Observation of Specialty Clinic - Suggested Outline:

During this specialty clinic, the resident should consider the following questions.

- What difficulties are patients having with their adaptive equipment?
  - How do these difficulties impact their functioning in home, school or work, and community settings?
  - Who is the person most likely to identify or describe the problems?
- What is the quality of communication between the professionals, the family members, and the patient?

  - Is the patient addressed directly?
  - Are suggestions for improvement elicited from the patient and family?
  - Are treatment options offered?
  - Are the patient and family involved in decision making?

- Do patients encounter any difficulties getting to the clinic (i.e., transportation, parking)?

- Does the adaptive equipment appear age appropriate?
  - Are there attempts to enhance the patient's independence?

- Are there any financial difficulties that could interfere with the patient's ability to acquire appropriate adaptive equipment?
  - Is insurance coverage adequate?
  - Are there restrictions, limitations, or timing issues imposed by the insurance company?

- What are the patients' and families' perspectives about the adaptive equipment clinic?
  - What are the perceptions of patient needs in home, school or work, and community environments?

- Are the needs identified by patients being adequately addressed?
- What types of social supports do the patients and their families have?
- Do the patients and families appear to be at ease in this clinic?

❖ What role should a physician assume regarding a patient's adaptive equipment needs?

- How can a physician be an effective team member?
- How can a physician communicate with the treatment team?

RESIDENT SELF EVALUATION: SPECIALTY CLINIC VISIT ADAPTIVE EQUIPMENT

Resident's Name:____________________

Date of Visit:____________________

Contact Person:____________________

Choose one child:

1. Who attended the clinic appointment for the patient you observed during this specialty clinic experience?

2. List two of the family's or caregiver's *strengths* and *resources*:

3. List the *concerns* or *needs* that were identified for this patient by the family or caregiver:

   a) Were these the same for everyone on the team? ☐ Yes ☐ No

4. Who typically identified the problems?

5. Who typically made suggestions for treatment and ways to address the identified problems?

6. What role did the primary care physician assume?

7. In what other ways could the physician participate?

8. Were treatment options given to the patient and family or caregiver such as adaptation of equipment; color or style of equipment, etc.?

9. Was the family or caregiver and patient equal partners in the decision making process? ☐ Yes ☐ No

10. Were efforts made to get feedback from the patients regarding comfort or effectiveness of the adaptations? ☐ Yes ☐ No

11. What kinds of follow up were needed for the patient you observed? (check all that apply)

☐ another clinic appointment

☐ phone contact between the CCMC physical therapist and the patient and/or family regarding decisions about adaptive equipment

☐ phone contact between the CCMC physical therapist and the patient and/or family to let her know how the new equipment is working

☐ the need to order new adaptive equipment

☐ consultation between the CCMC physical therapist and other health care or service providers

☐ the need to explore insurance reimbursement issues

☐ networking and resources for additional support for the patient and family (other patients with similar diagnosis, parent groups, organizations, and agencies, etc.)

☐ other:____

12. In terms of adaptive equipment, what future needs can you anticipate for the patient you observed (e.g., transitioning to a new school or college, job-related changes, housing changes, etc.)?

13. Which of the following behaviors did you observe of the individuals in attendance during these clinic visits? (check all that apply)

☐ clear and effective communication

☐ use of family friendly (non-jargon) language

☐ a willingness to listen to the patients and their families

☐ a willingness to listen to other professionals

☐ a Family Centered Care approach

☐ a collaborative spirit

☐ effective problem solving and decision making strategies

14. List the types or pieces of adaptive equipment that were being used by each patient.

15. Did the adaptive equipment appear age appropriate for each patient? ☐ Yes ☐ No

16. Did you have an opportunity to see any pieces of adaptive equipment that you had never seen before? If yes, please describe. ☐ Yes ☐ No

17. How were patients transported to the clinic appointments? (check all that apply)

☐ car

☐ medical van

☐ other:______________________________________

18. Was there any transportation issues? (check all that apply)

☐ parking

☐ ability of van to fit into public parking garage

☐ availability of handicapped parking spaces

☐ wheelchair lift problems

☐ transferring or lifting patient into or out of the vehicle

☐ other:______________________________________

19. Were insurance and/or Medicaid issues addressed during any of these appointments? ☐ Yes ☐ No

20. Was coverage or reimbursement for adaptive equipment a problem for any of the families or patients you observed? If yes, please describe. ☐ Yes ☐ No

21. Were there any evident limitations or restrictions imposed by insurance/Medicaid regulations? If yes, please describe. ☐ Yes ☐ No

22. Did this visit allow you to understand more about the challenges faced by patients and families related to adaptive equipment needs? ☐ Yes ☐ No

23. Did this visit enhance your understanding of the family's perspective of a clinic experience? ☐ Yes ☐ No

24. Do you understand more about the challenges faced by patients and families as they schedule and attend clinic visits? ☐ Yes ☐ No

25. Did you learn more about the benefit of families and professionals collaborating in the care of children with disabilities? ☐ Yes ☐ No

26. Did this visit allow you to discover new ways in which a physician might be helpful to families and children? ☐ Yes ☐ No

27. Were you satisfied with the preparation you were given for this experience? ☐ Yes ☐ No

28. Was this visit beneficial to you as a physician? ☐ Yes ☐ No

29. Were you satisfied with the experience and knowledge gained from this clinic visit? ☐ Yes ☐ No

30. What might you do differently in your practice as a result of this experience?

31. Is there anything you would like to see added to or omitted from this experience?

32. Did you have any difficulties during this experience? If yes, please describe.

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in the program visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: SPECIALTY CLINIC VISIT ADAPTIVE EQUIPMENT CLINIC

Preceptor's Name:____________________

Resident's Name:____________________

Name of Clinic:____________________

Date of Visit:____________________

The Resident:

1. Obtained information from family members about their priorities, concerns, and desired outcomes. ☐ Yes ☐ No
2. Demonstrate respect for the patient's and family's beliefs, values, culture, and customs. ☐ Yes ☐ No
3. Understood the challenges faced by patients and families related to adaptive equipment needs. ☐ Yes ☐ No
4. Understood the process of information sharing between the clinical team and the family. ☐ Yes ☐ No
5. Understood the benefit of families and professionals collaborating in the care of children with disabilities? ☐ Yes ☐ No
6. Demonstrated appropriate professional behavior. ☐ Yes ☐ No
7. Actively listened. ☐ Yes ☐ No
8. Communicated clearly. ☐ Yes ☐ No
9. Avoided using jargon when speaking with the family about the child's health care needs. ☐ Yes ☐ No
10. Asked questions when he/she was confused. ☐ Yes ☐ No

11. Overall, were you satisfied with this experience? ☐ Yes ☐ No

12. Did the resident arrive/depart at the scheduled time? ☐ Yes ☐ No
If no, please explain.

13. Were you satisfied with the format of this clinic visit for the Children with Disabilities Rotation? ☐ Yes ☐ No

14. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please explain.

Additional Comments:

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ADDENDUM*
ADAPTIVE EQUIPMENT SPECIALTY CLINIC

Below are descriptions of the primary diagnoses carried by most patients who are seen in the Adaptive Equipment Specialty Clinic. This is offered as a brief overview of these diagnostic categories; you are urged to do additional reading as needed.

CEREBRAL PALSY

Cerebral palsy is a disorder of movement and posture due to damage to areas of the brain that control motor function. Cerebral palsy can occur before, during, or after birth and typically becomes evident in infancy or early childhood. The motor impairment may affect different parts of the body and may include:

- Hemiplegia - involving the arm, leg, and trunk on the same side.
- Paraplegia - legs only (rarely seen in cerebral palsy).
- Quadriplegia - both arms and legs, as well as the trunk and neck.
- Diplegia - legs more involved than arms.
- Double hemiplegia - arms more involved than legs, and one side more involved than the other.

* *Adapted from: J. L. Bigge (1991).* *<u>Teaching individuals with physical and multiple disabilities</u>. New York: Macmillan Publishing Company.*

Involvement ranges from severe to mild. Factors include: a) level of independence in meeting physical needs; b) level of head control; c) amount of deformities that limit functioning or produce pain; and d) level of perceptual and sensory-integrative ability as they impact achievement of academic and age-appropriate motor skills.

In addition to the neuromotor impairment in cerebral palsy, there may be abnormalities of sight, hearing, speech, and sensation. Mental retardation and seizures may also occur with this condition.

In cerebral palsy, though the brain lesion does not progress with time, deformities can develop in the spine and extremities as the child gains length and weight. The most common descriptions of cerebral palsy include the area of injury within the central nervous system (pyramidal or extrapyramidal tracts); the muscle tone (hypertonia or hypotonia); the quality of muscle control (athetosis, dyskinesia, or ataxia); or mixtures of these.

Hypertonia is evident in approximately 60% of all cases of cerebral palsy. The motor cortex and spinal cord (pyramidal tract) are affected. Hypertonia is an increased stiffness that gradually causes limitation in range of motion and the development of muscle contractures. Deformities of the spine also develop with scoliosis (side-to-side curves) and/or kyphosis (posterior prominence; hip dislocation; and/or elbow, hand, knee, and foot contractures).

Hypotonia is a weakness, particularly in trunk and neck muscles. When mild to moderate degrees of floppiness persist through the first year without the emergence of spasticity or extrapyramidal (athetoid) involvement, generalized hypotonia is diagnosed. Many of the postural and movement mechanisms seen in hypotonic children are reminiscent of the infant at 4-8 months of age.

Children with hypotonia are usually late walkers, balancing responses are sluggish, and overall motor activity level is low.

When the brain lesion affects the extrapyramidal tract of the central nervous system, athetosis, choreoathetosis, or dyskinesia results. Extrapyramidal involvement produces involuntary movements. The arms, hands, and facial muscles are typically more involved than the legs. Choreoathetoid movements are wormlike and writhing.

Ataxia is the rarest type of cerebral palsy, occurring in only 1% of cases. The cerebellum is the primary site of injury and the main feature is an inability to achieve coordination in balancing and hand use. The individual bobbles while standing and walking, and "overshoots," often missing the object he or she is trying to reach. Constant efforts to stabilize can result in the eventual development of a rigid quality of movement.

The diagnosis of just one type of cerebral palsy is rarely appropriate. Mixed cerebral palsy is most common because brain damage is often diffuse. Thus, it is typical to encounter a diagnosis such as "mixed spastic/athetoid quadriplegia, with an apparent underlying ataxic component."

A diagnosis of cerebral palsy generally indicates that a multidisciplinary approach to treatment and physical management is necessary. Services of a physical therapist, occupational therapist, speech therapist, nurse, special education teacher, and classroom aide may be required.

Typically, students with moderate involvement require the greatest proportion of direct therapy time in an attempt to raise the student's level of independence and to prevent deformity. For students with severe involvement, therapists can train classroom educators and aides in positioning techniques and strengthening activities that can be used daily to prevent deformity and pain, and to enhance participation in classroom activities. Augmentative communication and power-driven mobility devices may also be required. Therapists then continually monitor equipment needs and provide consultation to the teachers. Students with mild impairment can usually be treated in groups with the aid of a physical educator who consults on a regular basis with the therapists and classroom teachers.

MUSCULAR DYSTROPHY

Muscular dystrophy is a hereditary disease characterized by muscle weakness that increases over time. There are several forms, of which the most common is Duchenne muscular dystrophy. Females usually transmit the condition to their male offspring, but are not affected themselves. The CPK enzyme (creatine phosphokinase) is elevated in the blood of those with muscular dystrophy.

Duchenne muscular dystrophy begins early in life, between the ages of 2 and 6 years, when the child is observed to have trouble climbing stairs and running. Weakness generally begins in the pelvic girdle muscles, but may occur first in the shoulder girdle muscles. Gradual loss of respiratory function is secondary to weakness of the abdominal and thoracic muscles. By age 10 to 14 walking usually ceases and wheelchairs are required. Individuals with muscular dystrophy need increased amounts of physical assistance with some school activities and with most, if not all, activities of daily living as their disease progresses. When children with muscular dystrophy become wheelchair users, severe spinal curvature and contractures in the flexors of the hips, knees, ankles, and feet typically occur. Three months of sitting greatly reduces the likelihood that an ambulating child will walk again. A period of illness that requires bed rest can also reduce the child's functional level.

Individuals with muscular dystrophy often live until adolescence or young adulthood. In the final stages, there is an increased incidence of respiratory infections. Death is usually caused by heart failure due to the weakened heart muscles or respiratory failure caused by the weakness of the chest muscles. Individuals with muscular dystrophy experience the psychosocial difficulties of any terminal illness.

SPINA BIFIDA (MYELOMENINGOCELE)

Spina bifida, a condition present at birth, is a defect in the closure of the vertebral bodies of the spinal column. There are three classifications of spina bifida:

- Spina bifida occulta - This is the mildest form in which protrusion of the spinal cord or its covering does not occur; only a few vertebrae are effected. The defect is not externally visible other than the occasional hairy patch over the defect.
- Meningocele - In this form the spinal cord covering protrudes through the open defect in the spine.
- Myelomeningocele - This is the most common form of spina bifida, characterized by the protrusion of the spinal cord and its covering through the defective vertebral opening. Presence of a myelomeningocele results in varying degrees of paralysis and loss of sensation in the lower trunk and lower limbs. The higher the spinal defect, the more severe the neurologic and functional deficits, including loss of sensation, weakness, loss of bladder or bowel control, joint deformities, and spinal curvature. Many individuals with myelomeningocele have an associated hydrocephalus characterized by head enlargement, brain abnormalities, and seizures. Hydrocephalus is caused by blocked cerebrospinal fluid drainage. It may be congenital or develop later.

Treatment of myelomeningocele is initiated shortly after birth with surgical repair of the bulging sac. Physical therapy is useful for gait training and teaching the use of mobility aids. Patients with myelomeningocele may be able to ambulate independently with the use of braces and crutches or may be nonambulatory, requiring a wheelchair at all times. Perceptual and other learning disabilities, attention deficits, and emotional difficulties are often found in children with myelomeningocele. Students may also have deficits in sensation that impact their ability to process information from touch, movement, position in space, and motor experiences.

APPENDIX E

Forms for Specialty Clinic Visit: Hospital For Special Care

SPECIALTY CLINIC VISIT
HOSPITAL FOR SPECIAL CARE

Location and Times:

You will be scheduled to attend the Hospital for Special Care for one half day (morning only) based on your schedule.

Hospital for Special Care
2150 Corbin Avenue
New Britain, CT
Telephone: (860) 827-4868

CONTACT PERSON:

John Pelegano, M.D.
Chief of Pediatrics

Format:

Attend inpatient rounds and observe the care of children with developmental disabilities in an intermediate care facility.

Resident's Responsibilities:

- Prior to attending the specialty clinic, please read the enclosed articles regarding primary care of children with developmental disabilities.

- During the clinic visit please follow these procedures:
  - Inform the preceptor that you are there to observe and learn about the long-term primary care of children with disabilities.
  - Follow the attending physician on rounds and discuss acute as well as chronic care issues.
  - Complete the *Resident Self Evaluation of the Specialty Clinic Visit.*
  - Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

SPECIALTY CLINIC VISIT GUIDELINES FOR HOSPITAL FOR SPECIAL CARE

Purpose:

- To gain a better understanding of how to provide care for children with disabilities and special health care needs, including: recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.
- To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.

Clinic Visit - Suggested Outline:

- During this clinic visit the following issues should be discussed:
  - The service delivery model in the Hospital for Special Care Pediatric Unit.
  - The appropriateness of the physical environment on the unit.
  - The ability of patients to receive early intervention or special education services during their hospital stay.

- The nature of the relationship between hospital personnel and early intervention or special education service providers.
- How the developmental (as well as medical) needs of children are being met.
- How the social and emotional needs of children are being met.
- How hospital personnel attempt to involve family members in the care of and planning for their children.
- How hospital personnel interacted with each other during rounds (i.e., "team" behaviors observed).

RESIDENT SELF EVALUATION: SPECIALTY CLINIC VISIT HOSPITAL FOR SPECIAL CARE

Resident's Name:____________________

Date of Visit:____________________

Contact Person:____________________

1. Who was present during rounds?

2. List two issues involving the care of children with disabilities discussed during rounds.

3. List two advantages to the use of large open-space rooms in the pediatric unit.

4. List two disadvantages to the use of large open-space rooms in the pediatric unit.

5. Do any patients receive early intervention or special education services in the hospital? ☐ Yes ☐ No

6. Do any patients attend school in the community during their stay at the hospital? ☐ Yes ☐ No

7. List two things you observed that show evidence that the hospital staff are attempting to meet the developmental (as opposed to medical) needs of children.

8. Was the physical environment generally age appropriate in terms of pictures, toys, family pictures, music, personal items, room decorations, etc.? ☐ Yes ☐ No

9. Whether present or not, how is the child's family incorporated into rounds and treatment considerations?

10. Briefly describe how related services (occupational therapy, physical therapy, speech and language therapy) are provided to children in the hospital.

11. List three different primary diagnoses for patients you observed during this visit.

12. Did this visit enhance your understanding of issues children face in an intermediate care facility? ☐ Yes ☐ No

13. Do you understand more about the challenges faced by families whose children are in an intermediate care facility? ☐ Yes ☐ No

14. Did this visit provide you with an understanding of how the clinical team processes, shares, and uses information? ☐ Yes ☐ No

15. Did you learn more about the benefits of professional collaboration in the care of children with disabilities? ☐ Yes ☐ No

16. Did this visit allow you to discover new ways in which a physician might be helpful to families and children? ☐ Yes ☐ No

17. Did you see examples of doctors integrating medical, educational, and social services for the children? ☐ Yes ☐ No

18. Were you satisfied with the preparation given for this clinic experience? ☐ Yes ☐ No

19. Was this visit was beneficial to you as a physician? ☐ Yes ☐ No

20. Were you satisfied with the experience and knowledge gained from this visit? ☐ Yes ☐ No

21. What might you do differently in your practice as a result of this experience?

22. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please describe.

23. Is there anything you would like to see added to or omitted from this experience?

Additional Comments:

As soon as possible, please return this form to:

Physicians Training Project Coordinator
University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
FAX: 679-1571

Thank you very much for your participation in the program visit and your honest feedback.

PERFORMANCE RATING BY PRECEPTOR: SPECIALTY CLINIC VISIT HOSPITAL FOR SPECIAL CARE

Preceptor's Name:______________________

Resident's Name:______________________

Date of Visit:______________________

The Resident:

1. Gained a sense of the family's priorities and concerns when their child is in an intermediate care facility. ☐ Yes ☐ No
2. Understood the challenges faced by families whose children are in an intermediate care facility. ☐ Yes ☐ No
3. Demonstrated an appreciation for the issues children face in an intermediate care facility. ☐ Yes ☐ No
4. Provided input about resources and services available for children with special health care needs and their families. ☐ Yes ☐ No
5. Understood the process of information sharing among the clinical team. ☐ Yes ☐ No
6. Demonstrated an appreciation of the challenges in meeting children's developmental needs in an intermediate care facility. ☐ Yes ☐ No
7. Had done extra reading about issues that children and families face at intermediate care facilities. ☐ Yes ☐ No
8. Demonstrated appropriate professional behavior. ☐ Yes ☐ No
9. Actively listened. ☐ Yes ☐ No
10. Communicated clearly. ☐ Yes ☐ No

11. The resident arrived/departed at the scheduled time. ☐ Yes ☐ No
If no, please explain.

12. Overall, were you satisfied with this experience? ☐ Yes ☐ No

13. Were you satisfied with the format of this clinic visit for the Children With Disabilities rotation? ☐ Yes ☐ No

14. Would you be willing to host another resident? ☐ Yes ☐ No

15. Did you have any difficulties during this experience? ☐ Yes ☐ No
If yes, please describe.

Additional Comments:

As soon as possible, please return this form to:

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University of Connecticut
Division of Child and Family Studies
263 Farmington Avenue, MC 6222
Farmington, CT 06030
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ADDENDUM*
HOSPITAL FOR SPECIAL CARE SPECIALTY CLINIC

Related Articles:

General Principles in the Care of Children and Adolescents With Genetic Disorders and Other Chronic Health Conditions, Pediatrics, Vol. 99 No. 4 April 1997.

Family-Centered, Community-Based, Coordinated Care for Children With Special Health Care Needs, Pediatrics, Vol. 83 No. 6 June 1989.

Community Physician's Role is Case Management of Children With Chronic Illness, Pediatrics, Vol. 84 No. 3 September 1989.

APPENDIX F

PRE-POST TEST: FAMILY CENTERED CARE MODULE

PRE-POST TEST: FAMILY CENTERED CARE MODULE

Resident's Name:____________________

Date:____________________

Please rate your level of comfort with the following concepts:

Not at all Comfortable	Slightly Comfortable	Reasonably Comfortable	Very Comfortable
1	2	3	4

	Not at all Comfortable	Slightly Comfortable	Reasonably Comfortable	Very Comfortable
1. The nine principles of Family Centered Care.	1	2	3	4
2. The specific elements involved in Cultural Competence.	1	2	3	4
3. The five components of Family Systems Theory.	1	2	3	4
4. The Medical Home concept as defined by the American Academy of Pediatrics.	1	2	3	4
5. The resources available at the Family Center at Connecticut Children's Medical Center.	1	2	3	4

APPENDIX G

Orientation Manual

Children with Disabilities Pediatric Rotation

Orientation Manual to the Three Year Residency Training Curriculum

Developed by:
The Division of Child and Family Studies
Department of Pediatrics
University of Connecticut Health Center

TABLE OF CONTENTS

APPENDICES

A: ROTATION SCHEDULE

B: ROTATION SCHEDULE FOR INTERNAL MEDICINE/PEDIATRIC RESIDENTS

C: GUIDELINES FOR IDENTIFYING CHILDREN WITH DISABILITIES OR SPECIAL HEALTH CARE NEEDS WITHIN THE CONTINUITY ROTATION

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 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; and
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 physicians 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 the literature (Blackman, Healy, & Ruppert, 1992; Brewer, McPherson, Magrab, & Hutchins, 1989; Committee on Children with Disabilities, 1992; Coury, 1990; Howard, 1982; McInerny, 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 diagnosis 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 Division of Child and Family Studies at the University of Connecticut Health Center 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, 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 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:

1. Increase comfort in communicating with children with disabilities and their families as demonstrated on the Resident Self Evaluation forms.
2. Acquire knowledge and skills that will enable you to address the medical, social, educational, and emotional issues affecting children with disabilities and their families as demonstrated on the Pre- and Post-Tests, Resident Self Evaluation, and Performance Rating by Preceptor forms.
3. Increase confidence in your ability to provide medical care to children with disabilities and their families as demonstrated on the Resident Self Evaluation and Performance Rating by Preceptor forms.

BEST COPY AVAILABLE

4. Be able to provide appropriate and effective primary medical care to children with disabilities and special health care needs within private, hospital, or community settings.

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 an 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 two to three learning modules to be completed in each of the three years, for a total of seven 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. An overview of the curriculum, the Rotation Schedule, may be found in Appendix A. The curriculum has been altered slightly to accommodate the Internal Medicine/Pediatric Residents 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 have been 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 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 seven 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 Care	Team Based Service Models: The Role of Other Professionals	Interagency Collaboration, Service Integration, and Resource Allocation
Early Intervention	Communication Skills and Team Participation	Advocacy and Responsibility & The Legislative Process
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 family of a child with disabilities or special health care needs in the family's home. Initially, you will be matched with a family by project staff. Eventually, all residents will identify families through their continuity clinic. 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 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 home-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 which 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 or Individualized Education Plan 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.

- **Special projects:** During the final block of the third year you will design a special 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 Division of Child and Family Studies.

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 OR SPECIAL HEALTH CARE NEEDS

Appendix C contains the Guidelines for Identifying Children with Disabilities 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 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; and
- provide comprehensive and coordinated care to patients with disabilities or special health care needs.

Additionally, you should always ask in the initial interview whether a 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 Division of Child and Family Studies. 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.

- **Pre-Tests:** There is a pretest for each module to assess your comfort 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.

- **Post-Tests:** The post-tests are the same as the pre-tests and are to be completed after each module. They are designed to assess an increase in your comfort level of the topic after completing each of the learning activities.

- **Annual Evaluation:** Each resident will meet the medical consultant once a year. The progress file and the individual portfolio will be reviewed. A written evaluation will be completed. A copy of the evaluation will be placed in your file at the Division of Child and Family Studies and at Connecticut Children's Medical Center.

EVALUATION SCHEDULE

Instrument	When to Complete	Who to Return it to
Module Pre-Tests	Prior to each Module	Project Coordinator or Session Preceptor
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
Post-Tests	Upon completion of each Module	Project Coordinator or Session Preceptor
Annual Evaluation	Annually by the Medical Consultant	Medical Consultant

RESPONSIBILITIES

- **Residents:**
  - Attend all didactic sessions and practicum experiences at scheduled time.
  - Bring curriculum materials/binder to all practicum experiences, including reading materials, guidelines, and 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 <u>Guidelines</u> and <u>Self-Evaluation</u> form 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 <u>Self-Evaluation</u> for each practicum experience.
  - Return all <u>Self-Evaluation</u> forms to the Project Coordinator.
  - Provide appropriate <u>Performance Rating</u> forms to a family member or preceptor for each practicum experience.

- Work with Project Coordinator to develop advocacy/special project for third year of residency.
- Complete the Advocacy/Special Project Proposal form.
- Develop and maintain individual portfolio.
- Participate in annual evaluation session per year with the Medical Consultant.

❖ **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, home-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 CCMC medical faculty, teachers, early interventionists, therapists, team participants, family members, and project staff, including the Medical Consultant.*

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APPENDIX A

ROTATION SCHEDULE

ROTATION SCHEDULE

	Component	Curriculum Content
	Module One: Family Centered Care	
	1	Orientation/Introduction to Family Centered Care
	2	Home visit arranged through the Division of Child and Family Studies
	3	Home visit with patient from continuity clinic
Y	4	Specialty clinic visit
E	Module Two: Early Intervention	
A	1	Introduction to Early Intervention
R	2	Observation of an Early Intervention program-home based services
	3	NICU Follow-up clinic visit
1	4	Open for catch-up visit or resident's special interest
	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
	Module Four: Team Based Service Models: The Role of Other Professionals	
	1	Introduction to Team Based Service Models: The Role of Other Professionals
	2	Observation of assessment or intervention (PT, OT) followed by interview with the interventionist
Y	3	Observation of assessment or intervention, (SP, Audiology) followed by interview with the interventionist
E	4	Specialty clinic visit
A	Module Five: Communication Skills and Team Participation	
R	1	Introduction to Communication Skills and Team Participation
	2	Family interview regarding experiences with various disciplines and team process
2	3	Observation of a team meeting for Early Intervention or Special Education in an elementary, middle or high school
	4	Participation in a team meeting (specialty clinic, continuity clinic, IFSP, IEP)
	5	Participation in a team meeting, IFSP, or IEP for a child from continuity clinic
	6	Open for catch-up visit or for resident's area of special interest
	Module Six: Interagency Collaboration, Service Integration, 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
Y	5	Open for catch-up visit, advocacy project guidance, or resident's area of special interest
E	Module Seven: Advocacy and Responsibility and The Legislative Process	
A	1	Introduction to Advocacy and Responsibility and The Legislative Process
R	2	Observation of a legislative hearing, public hearing, or task force
	3	Meeting with a legislator
3	4	Observation of State Interagency Collaborating Council or advisory council
	5	Advocacy project
	6	Advocacy project
	7	Advocacy project
	8	Recap/closure

APPENDIX B

ROTATION SCHEDULE FOR INTERNAL MEDICINE/PEDIATRIC RESIDENTS

ROTATION SCHEDULE FOR
INTERNAL MEDICINE/PEDIATRIC RESIDENTS

	Component	Curriculum Content
	Module One: Family Centered Care	
Y	1	Orientation/Introduction to Family Centered Care
E	2	Home visit arranged through the Division of Child and Family Studies
A	3	Specialty clinic visit
R	**Module Two: Early Intervention**	
	1	Introduction to Early Intervention
1	2	Observation of an Early Intervention program-home based services
	Module Three: Special Education	
	1	Introduction to Special Education
Y R		Observation of a Special Education program in elementary, middle, or high school
2		Early Intervention or school visit with patient from continuity clinic
	Module Four: Team Based Service Models: The Role of Other Professionals	
Y	1	Introduction to Team Based Service Models: The Role of Other Professionals
E	2	Observation of assessment or intervention (PT, OT) followed by interview with the interventionist
A	3	Observation of assessment or intervention, (SP, Audiology) followed by interview with the interventionist
R	**Module Five: Communication Skills and Team Participation**	
	1	Introduction to Communication Skills and Team Participation
3	2	Observation of a team meeting for Early Intervention or Special Education-either arranged by the Division of Child and Family Studies or by the resident with their continuity clinic patient
	3	Specialty clinic visit
	Module Six: Interagency Collaboration, Service Integration, and Resource Allocation	
Y	1	Introduction to Interagency Collaboration, Service Integration, and Resource Allocation
E	2	Family interview on integrated care and funding sources
A	3	Agency administrator interview
R	**Module Seven: Advocacy and Responsibility and The Legislative Process**	
	1	Introduction to Advocacy and Responsibility and The Legislative Process
4	2	One visit to the capitol-either observation of a legislative public hearing or task force or meeting with a legislator
	3	Observation of State Interagency Collaborating Council or advisory council

APPENDIX C

GUIDELINES FOR:

Identifying children with disabilities and special health care needs within the continuity rotation

GUIDELINES FOR IDENTIFYING CHILDREN WITH DISABILITIES 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
- 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, day care 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)

APPENDIX H

Session Information Form
Resident Evaluation Forms

Debriefing Sessions

As the medical consultant debriefs the resident, he/she should cover the following areas:

1. Feedback on the curriculum and process
    a. didactic sessions
    b. community visits
    c. specialty clinic visits
    d. written material he/she has received

2. Application of material within his/her practice OR no application
    a. understanding of material in general
    b. understanding of physician's role
    c. understanding of material and how to use it
    d. how he/she has used the material in practice or why they have not
    e. if needed: answer any questions he/she may have and help her/him apply information

3. Review file
    a. self evaluations
    b. preceptor evaluations

4. Portfolio

Children With Disabilities Rotation
Debriefing Session
Year One

Name of Resident ____________________

Physician's Level ____________________

Date ____________________

Person Completing Form ____________________

1. *What is the resident's overall satisfaction with the curriculum?*
   a. didactic sessions (format, content, relevance)
   b. home visits
   c. community visits/program visits
   d. specialty clinics

2. *Does the resident have an understanding of the material in year one and the doctor's role? Please explain.*

3. *Is the information from the curriculum currently being used and if so, how is it being applied?*(general outpatients, specialty outpatients, inpatients) *If not, why not?*

    1. application or observation of family centered care principles

    2. referral to or contact with early intervention program, discussion with early intervention program

3. *Has participation in NICU Follow-up Clinic altered the resident's approach to the premature infant in the NICU? How?*

   a. How has participation in NICU Follow-up Clinic altered the resident's approach regarding non-medical issues?

4. *What experiences have most influenced the resident (both positively and negatively)?*

   a. How have these experiences altered the resident's management in general and for a specific patient?

How does the resident envision that this rotation (curriculum) may affect his/her future practice?

6. *Does the resident have any medical or non-medical concerns regarding the curriculum or his/her patients?*

7. *Current patients to follow up on:*

8. *Are there any pending issues or concerns that should be addressed at the next debriefing session?*

9. *Comments/recommendations*

10. *Medical Consultant's comments:*

The resident's Progress File was reviewed: Yes ______ No ______
The resident's Portfolio was reviewed: Yes ______ No ______

The information upon which this debriefing form is based has been discussed with the resident: Yes ______ No ______

House Officer Signature: ____________________ Instructor Signature: ____________________

Children With Disabilities Rotation
Debriefing Session
Year Two

Name of Resident

Physician's Level

Date

Person Completing Form

1. *What is the resident's overall satisfaction with the curriculum?*

    a. didactic sessions (format, content, relevance)

    b. home visits

    c. community visits/program visits

    d. specialty clinics

2. *Does the resident have an understanding of the material in year two and the doctor's role? Please explain.*

3. *Is the information in the curriculum currently being used and if so, how is it being applied? If not, why not?*

   a. knowledge of the roles and educational backgrounds of different professionals

   b. knowledge of team process, participation on teams, facilitation of teams

   c. communication skills

4. *What team meetings has the resident participated in or observed during inpatient, outpatient, specialty clinics, not part of this curriculum? (e.g. discharge planning, NICU, CCMC floor, etc.)*

5. *How has year 2 of this curriculum influenced the resident's approach to working with different professionals and working on teams? (Has any experience in particular influenced the resident positively or negatively?)*

6. *How might this curriculum alter the resident's approach to and participation in team meetings in his/her future practice?*

7. *Does the resident have any medical or non-medical concerns regarding the curriculum or his/her patients?*

9. *Are there any pending issues or concerns that should be addressed at the next debriefing session?*

10. *Comments/recommendations:*

11. *Medical Consultant's comments:*

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reviewed: Yes ______ No ______

Portfolio was reviewed: Yes ______ No ______

upon which this debriefing form is based has been discussed with the resident: Yes ______ No ______

nature: ______________________ Instructor Signature: ______________________

Children With Disabilities Rotation

Evaluation Form

Year Three

Name of Resident ____________________ Physician's Level ____________ Date ________ Person Completing Form ________________

Based on preceptor evaluation responses, check whether the resident's performance was acceptable or unacceptable.

I. Interagency Collaboration, Service Integration, and Resource Allocation

	Acceptable	Unacceptable	N/A	Record Not Available	Date and Visit
A. Didactic Session					
1. Participation	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	
B. Interviews of Two Families					
1. Independence	☐	☐	☐	☐	
2. Satisfaction with performance	☐	☐	☐	☐	____________
3. Reliability	☐	☐	☐	☐	____________
C. Interviews of Two Agency Administrators					
1. Independence	☐	☐	☐	☐	
2. Satisfaction with performance	☐	☐	☐	☐	____________
3. Reliability	☐	☐	☐	☐	____________
D. Debriefing					
1. Satisfaction with performance	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	
E. Self Evaluation forms completed	____/____				

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Based on preceptor evaluation responses, check whether the resident's performance was acceptable or unacceptable.

II. The Legislative Process

	Acceptable	Unacceptable	N/A	Record Not Available	Date and Visit
A. Didactic Session					
1. Participation	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	
B. Community Visits					
1. Satisfaction with performance	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	______
C. Interview a Legislator					
1. Satisfaction with performance	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	______
D. Self Evaluation forms completed	____/____				

III. Advocacy and Responsibility

	Acceptable	Unacceptable	N/A	Record Not Available	Date and Visit
A. Didactic Session					
1. Participation	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	
B. Advocacy Project					
1. Independence developing project	☐	☐	☐	☐	
2. Independence implementing project	☐	☐	☐	☐	
3. Satisfaction with performance	☐	☐	☐	☐	
4. Reliability	☐	☐	☐	☐	
C. Self Evaluation forms completed	____/2 (Project Proposal and Self Evaluation)				

IV. Extra Visit

	Acceptable	Unacceptable	N/A	Record Not Available	Date and Visit
A. ______					
1. Satisfaction with performance	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	______
3. ______	☐	☐	☐	☐	
B. ______					
1. Satisfaction with performance	☐	☐	☐	☐	
2. Reliability	☐	☐	☐	☐	______
3. ______	☐	☐	☐	☐	

Based on preceptor evaluation responses, check whether the resident's performance was acceptable or unacceptable.

IV. Extra Visit (continued)

	Acceptable	Unacceptable	N/A	Record Not Available	Date and Visit
C. ______________________					
1. Satisfaction with performance	☐	☐	☐	☐	______________
2. Reliability	☐	☐	☐	☐	
3. ______________________	☐	☐	☐	☐	
D. Self Evaluation forms completed	____/____				

V. General Qualities

A. Flexibility	☐	☐	☐	☐
B. Reaction to criticism	☐	☐	☐	☐
C. Ability to work with professional staff	☐	☐	☐	☐
D. Overall performance	☐	☐	☐	☐

Medical Consultant's Comments:

Overall impression of the resident's understanding and integration of the material: Poor Fair Good Outstanding

The information upon which this evaluation is based has been discussed with the resident: _______ Yes _______ No

House Officer Signature: ____________________ Instructor Signature: ____________________

Children With Disabilities Rotation Evaluation Form
Resident Feedback

Name of Resident ____________________

Physician's Level ____________________

Date ____________________

1. Overall satisfaction with curriculum:

2. Experiences that most influenced you:

3. Relevance of curriculum:

a. to current practice

b. to future practice

4. Clarification needed regarding curriculum, specific patients, other:

5. **Do you have any recommendations for changes?**

6. **Comments** (please use back of page if needed):

ROTATION IN CHILDREN WITH DISABILITIES
EVALUATION FORM

Name:_______________________________________

Period of Rotation:_______________________________

Form completed by:_______________________________

Pediatrics
PL-1 :____
PL-2 :____
PL-3 :____
Med-Peds
PGY__:___

The following numbers/codes represent the level at which the preceptors find the above to have performed on this rotation based on feedback reports:

1: **Outstanding:** (the resident's performance was *exceptional* in this area, showing *advanced abilities*)
2: **Above average:** (the resident performed at a *level above* that generally expected or found)
3: **Average:** (the resident performed at the level *expected* for his/her level of training)
4: **Fair:** (the resident's performance was *acceptable* but may need work in this area)
5: **Poor:** (*remediation* regarding this area of the resident's performance is suggested but requirements were fulfilled)
6: **Inadequate:** (the resident's performance in this area was unacceptable and remediation is (required/recommended)
NA: **Not Applicable** or not assessable for this resident

* *

Level of Performance

I. PROFESSIONAL ATTITUDES AND BEHAVIORS:

Promptness _____
Reliability (notification of sites if delayed or unable to attend) _____
Availability (including use of beeper when off site) _____
Working with faculty/and staff _____
Working with community preceptors _____
Displayed professionalism _____
Response to criticism (if applicable) _____
Flexibility _____
Number of absences due to resident circumstance _____

III. COMMITMENT TO SCHOLARSHIP:

Delivery of forms _____
Assigned readings _____
Participation in discussion during didactic sessions. _____
Didactic sessions:

____

____

____

Advocacy Project _____
Independent Portfolio Collection _____
Number of self evaluations done/number required __/__
Number of forms still due _____

Review for ______________________________________in Children With Disabilities Rotation

III. HUMANISTIC QUALITIES:

Appreciation of different perspectives with regard to issues with families and children with disabilities _____

IV. MORAL AND ETHICAL BEHAVIOR:

Perceived doubts or clear violations of general standards of moral and ethical behavior would be discussed under "Additional Comments".

_____please see

* *

**** No procedures are certified on this rotation. ****

* *

ADDITIONAL COMMENTS:

THIS HOUSE OFFICER *HAS / HAS NOT* COMPLETED THE FACULTY SET REQUIREMENTS FOR SUCCESSFUL COMPLETION OF THIS ROTATION

The information upon which this evaluation has been based has been discussed with the resident:

_____Yes _____No

House Officer Signature____ Date___________

Instructor Signature____ Date___________

APPENDIX I

Debriefing Summary Report

APPENDIX I
Debriefing Summary Report

Personnel Preparation Grant
Component two: Pediatric Residents
An Exploration of Attitudes, Experiences, and Feedback

The pediatric residency rotation in children with disabilities is made up of a three-year longitudinal curriculum. The curriculum originally consisted of nine modules that were condensed to seven modules in the final year of the project. These modules were entitled: Family Centered Care, Early Intervention, Special Education, Team Based Service Models: the Role of Other Professionals, Communication Skills and Team Participation, Interagency Collaboration, Service Integration and Resource Allocation, and Advocacy and Responsibility and the Legislative Process. Within each module, the resident participated in different practicum experiences, for example, home visits, special education program visits, and specialty clinic visits (i.e. Genetics).

Evaluation strategies included both process and product measurements. Process measurements include self-evaluations, preceptor feedback, family feedback, and meetings with the supervisor and medical consultant. Product review included pre/post knowledge questionnaires, portfolio review, and satisfaction surveys.

The Medical Consultant's responsibilities included conducting a biannual debriefing with each resident to obtain feedback on all areas of the curriculum, inquire about the resident's integration of the project's content into their ongoing residency program and answer any questions. These meetings produced qualitative data. Through evaluation of this data, themes emerged. The following report communicates this data.

Method

The residents were debriefed by the Medical Consultant based on their rotation schedule. This report is based upon 18 debriefings sessions, with 16 different residents. The Medical Consultant addressed the following topics relevant to whatever areas that particular resident had covered at that time:

1. Feedback on the curriculum and process
   a. didactic sessions
   b. community visits
   c. specialty clinic visits
   d. written material he/she has received

2. Application of material within his/her practice OR no application
   a. understanding of material in general
   b. understanding of physician's role
   c. understanding of material and how to use it
   d. how he/she has used the material in practice or why they have not
   e. if needed: answer any questions he/she may have and help her/him apply information

3. Review file
   a. self evaluations
   b. preceptor evaluations

4. Portfolio

The sessions were taped recorded with the resident's knowledge and permission. The tapes were then transcribed. Each debriefing session lasted between 45 minutes to 1 ½ hour, depending on the responsiveness of the resident. The original debriefings sessions were taped, but not transcribed. In these cases, the Medical Consultant listened to the tapes and recorded information onto debriefing forms by hand. Each transcription and debriefing form was coded for any emerging themes.

Findings

This report was prepared by the Project Coordinator. It is essentially a summary of the information that was gathered in the debriefing sessions. It focuses on the resident's perspectives and attitudes about the Children with Disabilities Rotation.

Application

The residents have applied the knowledge that they have learned in this curriculum in different ways in their practice. The residents applied the newly acquired knowledge by making referrals; advocating for patients and families; collaborating with families, school systems, and Birth to Three programs; conducting more thorough examinations, providing added support to families; and knowing what knowledge they will need to acquire to continue support in future practices in other states.

Many of the residents have utilized their knowledge on Birth to Three to make referrals to the program. The residents have found success in making these referrals; for example, one, second year resident has referred five patients to Birth to Three, three of whom were found eligible for services. Another second year resident referred four patients with developmental delays to Birth to Three. All four children were found eligible for services. A first year resident has made, "just one [referral] in my own practice, I just referred [a child] who probably has mild CP. And she's going to come and see Neurology and she's going to see Orthopedics as well for some gait problems." And still another first year resident made one referral. She says, "Really it's just one patient that I've referred. I do have other patients in my practice who had received Birth to Three, but his kiddo, again, he was a former NICU baby, was giving us a suggestion of some physical problems and I made the referral to Birth to Three, and he now receives physical therapy services in the home..."

The Medical Consultant also states that one resident, while working on inpatient service, referred at teenage mother, who has a child with developmental delays (hospitalized at the time), to the Family Center at CCMC. The resident did this to help support this mom, who was overwhelmed and needed assistance obtaining services in the home. This resident utilized the information she learned in the Family Centered Care module about the Family Center to get this mom some assistance.

When a child was admitted to the inpatient service, the mother complained that the child doesn't hear. The resident referred the child to the Speech and Audiology Department.

Residents are also using their knowledge of early intervention, special education and the law to not only advocate for their patients but to also make the connection between the medical field and the Birth to Three programs or the schools. They are beginning the process of collaboration and team work. A second year resident tells us about a mom who went doctor shopping for months. The mom didn't feel any of the primary care providers were listening so she kept looking. When the resident got involved, she really listened to mom and was then able to make a diagnosis and continue on with the referral to Birth to Three. She then became a part of the team: "I had the opportunity, as I said, to follow this family from the very beginning. I was the one who made the phone call [Birth to Three referral]. Then I made the home visit, and we actually came together and worked on the paperwork and set the goals for the patient, for the IFSP." As part of the team, the resident was very aware when it came time for the child to transition into the school system. She kept up to date on the transition proceedings and attended one of the meetings. The school system wanted to place the child in a segregated setting. "I was aware that this was going to be a temporary placement from the time that Reynaldo turns 3 to...maybe through the summer, but I still thought it was not going to be appropriate." So the resident communicated by phone with, "not just the people that are intervening in the services but pretty much the people on the school board." Because of this resident's advocacy efforts, the child was put into an appropriate, inclusionary setting; the mom was thrilled.

Another resident contacted the school system on one patient with ADHD, "He has spoken to the teacher of one of his school-aged patients with ADHD about the need for smaller class/group size, change in his location in the classroom," says the Medical Consultant about a second year resident. And still another resident intervened on behalf of her patient who was going to lose his services in the school system. The Medical Consultant states, "Because the child lacked a specific diagnosis, his services were going to be discontinued. T, who now knew the special education law from her didactics, knew that her patient was eligible for these services, found a way to continue them. She functioned as an extremely effective link between her patient and the school."

Residents have also used the information they have learned in the didactics and the visits they have experienced to help support the family and make their examinations more thorough. One residents tells us that it is good to know the process so "...just to kind of let them know how it's all going to work out because, you know, for them it's kind of [scary]..." Another resident describes how the actual community visit made him more comfortable in the process. He can now support families:

> I was actually in the room, so I can even describe the room, tell the parents, you know this is going to happen with the toys, they're going to come out, and remembering the people that are involved and who closely work with the children, and then explain the detail of how the testing is going to go. Yeah, I definitely feel more comfortable. I've been there.

That same resident was able to use her experience to put the family at ease in making a decision to go to the audiology department for an evaluation. This resident is helping his families feel more comfortable with the process and making additional recommendations. The resident goes on to say, "...giving them [the family] confidence I know exactly what the child is going to go through and when you see audiology this is exactly what's going to happen in a non-threatening way, the family agreed with it." Still another resident commented on how this rotation helps him know, "what to expect, most definitely."

One resident does not feel that she can effectively apply the information learned in the Family Centered Care didactic session, she tells the Medical Consultant that,

> I think perhaps... I can't think of any specific ways to change the curriculum, but keeping in mind that interns are ***really*** not quite capable of being the institutor of the Family Centered Care module because of our level of training and our level of expertise but that it's something that would sort of be a nice goal for third year... as perhaps the only thing.

Yet, the Medical Consultant explains that a different resident "provided concrete recommendations for a child after discharge [from the NICU] which gave the family hope and orientation towards the future." Due to this curriculum, this resident also is now able to ask "questions about services a patient may be receiving [that] are much more informed and direct" and "she uses her knowledge wherever she is, continuity clinic, walk-in, inpatient service." The disabilities rotation is assisting in the overall goal of residency as the resident is "incorporating all that she has learned through didactics, visits, and observation into her daily medical management, not to her disabled patients/families only" and

> ...she is better able to see 'things' from the child and family's perspective. She asks more questions, more detailed questions of all patients, but especially those with definite or possible disabilities.

Three residents, in particular, have pointed out how they will be able to apply the knowledge they have learned to their future practice. Knowing all that it takes and applying her knowledge in primary care medicine for children with disabilities in Connecticut, a second year resident knows already that she "wants to establish a network" in her own state. "I want to get to know the people who, like here in Connecticut, I could call if I need to make not just a referral, but just a plain question on, you know, making the transition from Birth to Three to the school system. So, I need to really get started with my network." Another resident realizes that now that he knows the laws and other information about Connecticut, he will also need this information about the state he will practice in. He says he needs to know, "...what the state laws are there, too. You know, as far as Birth to Three and what have you." Lastly, the other resident has taken from this curriculum the "skills that are crucial for him to learn in order to do emergency medicine successfully. These skills are (1) ability to examine the patient in a wheelchair, (2) improved communication with the patient and the family, and (3) ability to see the patient's problems from the family perspective."

Some residents have generalized this information and the knowledge learned in this rotation to apply with many different families. To one resident, "this [disabilities rotation] has made the difference in terms that I understand the whole process and I feel very good about getting feedback, about the family getting the actual services that they need." A second year resident states,

> So, how would I take that home to my practice? Just the concerns of the family members. It goes beyond patient care. It goes beyond medical issues. It goes beyond the normal otitis and the strep. You know, there's a lot more issues underlying once they leave your office, and what's available to them and how could we access it easier and make their life a little easier lifestyle... for the parent as well as for the child.

Another resident says pediatricians should

> ...just be a stern advocate for the families, for the patients, that we can be an active participants and not just the diagnosis but the entire process for a patient's life and what the outcome will be. We can make a difference.

One resident commented that now that she got one baby into the system, "getting the other baby into the system is not as difficult." And still another resident tells us how she spent the morning with a family, watching them get ready to go to a subspecialty clinic visit. She realized at that point how difficult an early morning appointment would be for him or another child with disabilities. Lastly, a different resident shares, "I recognize that I'm lucky to have the opportunity to learn about this, and I think it will make me a better pediatrician when I'm done."

Recognition of the Doctor's Role

Residents are indicating in the debriefing sessions that they are developing a better understanding of what their role is as pediatricians in the lives of children with special needs and their families through the experiences in this rotation. These residents see their roles as a doctor who can respond to different needs of the patient and family, not always medical needs; who knows about available resources; and who advocates for their patient.

One resident went to the home of a child with a disability and spent some time there. She explains,

> But that was really an eye opening experience because you get to see the little stuff and how it impacts on their life, and the big stuff, too, and how it changes that family and how the caregivers need to respond to that and need to address the needs of this family which aren't just her son's medical needs.

This resident sees part of her role as responding to the family's needs, which are not always medical. Another resident also recognizes the doctor's role in helping the family, pointing out that the patient or child should be seen in the context of the family and not just individually. She states,

> I am very proud and happy to say that this curriculum has made me a better person and a better resident, to help my patients in difficult situations, to help the family -- not just the patient but the entire family – and that I feel that other residency programs really need to get on the ball and start similar curriculums for their residents because it's greatly needed.

Another resident speaks about the doctor's role in knowing about resources in order to better support families. He uses his knowledge of Birth to Three to help address parental concerns. He says, "...parents are sort of surprised that there's something out there like that [Birth to Three] and you know, I think it's good for me to know about it, because it's something that we [doctors] can do, you know to intervene if parents have concerns..." Another resident has taken this a step further when she indicates that she has a part in her patient's transition to the school system; "He's going to be three, and that's my next portion." She recognizes her role as a member on the team. As a team member, the doctor's role is also to help facilitate the goals of the child with the therapists and the family,

> I always ask them (Birth to Three Providers)...How can I make this better for you? How can I facilitate in your work and in making sure that we achieve the goals for the child? And a lot of what I hear is more communication.

This same resident sees the doctor's role also as an advocate for their patients,

> I have a particular interest in advocacy, and I don't think I'm being very active so far because the residency is very time consuming, but I think at another point it'd be able to benefit a large group of patients in terms of advocacy.

Evidence of Learning

The Children With Disabilities rotation is meant to teach the residents, as well as, expose them to new material and experiences. The following are quotes from the residents or statements from the Medical Consultant that demonstrate evidence of learning in Family Centered Care; Birth to Three; special education; law; roles of different professionals; communication skills; and resources. They are grouped by category.

Family Centered Care

"I think it's helpful in that it got... it helped me to understand the importance of family-centered care."

"I feel very strongly the parents should be involved in quality of life issues about their kids from the very beginning."

"There's a lot about the visit [I would carry away with me]. How a family interacts with the children. What their lifestyle is like outside of your office. When they go home, what do they do? And that you never see, you know, on a personal basis you never see that. How many things that we take for granted is such a tremendous act for them. You know, getting up and getting dressed, getting the kids just eating is a major effort, where we don't even think of that normally."

"It has <u>*certainly*</u> made me much more aware of the social and psychological stress that having a child with a disability places on parents."

The resident will be less aggressive in attempting to feed an infant with clear oral aversion, as she feels that by pushing the oral feeding, the aversion will worsen of the long term. She learned this during her home visit.

The resident realized that many of his PCC patients have a language barrier and that his patients are more likely to be able to "do more" at home, in their own environment. He feels strongly that any full-scale, comprehensive, patient/family assessment requires a good translator.

The resident feels that he has a much better understanding of the services available and the hurdles families must get over. As a result, the questions he asks are more informed and informative.

The resident understands better what families go through to obtain necessary services for their children.

The resident has taken from this curriculum, skills that are crucial for him to learn in order to do emergency medicine successfully. These skills are (1) ability to examine patient in wheelchair (2) improved communication with patient and family, and (3) ability to see patient's problems from family perspective.

The resident spent the morning with child M (at M's home), watching him get ready for appointment at neurosurgery. She realized how difficult an early morning appointment would be for him or another child with a similar disability.

Birth to Three

"I knew very little [about Birth to Three]. I knew that there was a child with a need, you make a phone call, you talk to the person who is doing the intake. You give them information. And that's the end of it, and perhaps you're lucky enough in a few months to get some kind of feedback... from the family and some paperwork. But, with this curriculum it has become a reality in my... for this family. It makes sense to me now."

"Which, I think is a good thing, because I didn't really know much about it [the Birth to Three program and process] before this, so..."

"And I think being in the NICU I definitely realize the importance of programs like NICU follow-up and early intervention and how are these families going to support these kids when they went home."

"This [actually doing a referral, being involved in the making of the IFSP and the transition process from Birth to Three to the school system] has made the difference in terms that I understand the whole process and I feel very good about getting feedback, about the family getting the actual services that they need."

Medical Consultant says: "But I love the way IFSP rolled so easily off your tongue. Did you know about that before? Is it just something that you learned here, or...?"
Resident replies: "It's something that I think I learned actually during the didactic."

The resident was able to watch a playgroup of children with disabilities in Manchester, appreciate its strengths (parents sharing experiences and advice) but also note weaknesses (no non-disabled children), not natural environment (segregated at a school).

Special Education

"Well, at PCC I've had people who have been concerned about things at school who didn't know they didn't have the right to a PPT. So, that's kind of... I've had a few families that that's happened with. And I've told them, you know, don't let them change the classroom setting until you've had the PPT."

"I know how they have all that inclusion and it has to be 20% of the class, it should be... the disabled child should be about 20%."

"The history I didn't know."

Law

"And also getting, and I know the laws that apply federally will apply also in Florida, but I also need to get to know more of the other state laws and how the programs are different. Because I know they're not going to be the same."

"...they were saying what they think is appropriate once they're out of Birth to Three and they go to special ed. what the... the law is written so that it says what is appropriate education, what is appropriate environment, and what we think - maybe as parents or health care providers view as appropriate might not... the people who are actually in the school system might have a different definition of appropriate."

"And it was good. A lot of things were reinforced from the early intervention and from the family visit and Birth to Three. That was in the beginning it was reinforced, and put a perspective on what special ed. actually is and what acts – the IDEA act and everything else that goes into play. So, that was pretty good."

Different Professionals

"...and there were two... I think they were health care professionals, or I think one was an OT and one was a Physical Therapist. Which in and of itself was pretty good to know the difference of what their rules are and how they're different, because I always say OT/PT. I don't... I never know what, you know, what handles what or whatever, so... So to hear them speak about the roles was very informative."

"Like getting OT, you know, I think I know what that means now, rather than, you know, just another person seeing them. I know what they're actually doing. I think that's valuable. Same thing with speech too. I think that's valuable."

"But I think I have a better grasp of what it (OT vs. PT) is in my head."

Communication Skills

The resident has improved communication skills with parents of disabled children, especially in emergency department, this allows him to better care for theses children when they come to the ED with respiratory distress, or other acute problems. He is better able to examine these children, he's not so put off by orthotics or other assistive devices.

The resident feels that she can help families cope with the disability of child by providing concrete recommendations for management – medical, social, educational.

Resources

"So, just to know there are differences in the programs and resources I think is good."

"Well, when we got there not only like I said did she show me what went into fitting and kind of the technical stuff about the chair, but she really with every patient would show me what she really had to write out to document for the insurance companies to get them to approve it. And it's quite extensive. It was like a four or five page letter documenting range of motion and essentially the different needs and why this child needed a custom fit wheelchair. And so, because it's easy for us to say, 'well, I think this child needs a custom wheelchair. Go get a wheelchair or we'll send him to the wheelchair clinic.' But to understand that the process is really very, very involved and complicated."

She is more aware of other services, e.g. availability of Birth to Three, social services, etc, for babies and families when discharge from NICU.

Evidence of learning but not from this curriculum

"Well, I would say I hear differently, but I'm not necessarily sure it's because of this curriculum. I think it's more of just going through the residency, you know. And just knowing more and knowing what to look for as far as medical and developmental problems."

Change in Attitude

With increased knowledge, residents have had a change of heart. They are more comfortable, confident, enthusiastic, and willing to advocate for patients.

A second year resident reveals, "I'm more enthusiastic about taking care of these kids, instead of being more, like, shying away from it. Rather than accepting, seeing it as a challenge, and accepting it."

Another resident not only learned from her home visit experience, but the visit changed her "passion" for the work she does with children with disabilities. She explains,

> I think it changed my passion for making sure that the details of these kids get looked after, especially with the moms who don't have the resources that this mom on this home visit did. So…and I think it also made me realize the importance of early intervention, and I got to see first-hand how powerful an impact it can have and is one that doesn't depend on good insurance or money or educated parents.

One can see this resident's passion, as she talks about the challenges and how she wants to take them on, she says,

> Actually, I found that to be the most interesting challenge, and again one where I don't feel like I have a good understanding on how to make that happen (getting a child with a disability into a day care), but certainly I would have loved to called up a day care and told them, 'hey, you have to take this kiddo' – you know, he's just like other kids… he just can't walk, you know. But that was really an eye opening experience because you get to see the little stuff and how it impacts on their life, and the big stuff, too, and how it changes that family and how the caregivers [physicians included] need to respond to that and need to address the needs of this family which aren't just her son's medical needs.

As one resident discloses that she is more confident about the Birth to Three process, another resident explains to the Medical Consultant that she is more comfortable with children with disabilities and birth defects. Still a different resident reveals how her newly acquired knowledge makes her happy to be able to support families,

> I am happy that I know about Birth to Three because I know which kids are… I know that I should be referring kids, and I know that even if it's a referral that is declined for services it's still a worthwhile thing to do, and that makes me happy. And I'm glad that I know about the project Dr. Dworkin is doing as another alternative…Child Serve…if Birth to Three is not an appropriate referral. I just think that it's better, especially in our patient population and the side of referring and the side of trying to hook up parents into a support network.

A resident explains now that she knows about Birth to Three and the transition process into the school system, she feels like she can make a difference, she is needed in this process and that makes her want to advocate. Lastly, a resident feels that watching the application from the didactic sessions and during community visits makes him better able to assess the appropriateness of a child's school placement.

Change in Behavior

Residents have taken the knowledge learned and altered how they do things. After review of the debriefings, it is found that the changes involve referrals, examinations, family centered care, assessment of programs, and recommendations.

We have found that some residents have changed what referrals they make, how they make them and how the doctor talks to the family about them. One resident talks about Birth to Three more with families now: "And knowing there are things we can do for these kids and speaking to them about Birth to Three, I think is something that I'm doing more." Another resident explained to the Medical Consultant that this curriculum has opened her eyes, especially with regards to what to do with children that are developmentally disabled, Birth to Three, speech therapy, and audiology. She will now take all the appropriate steps to refer and follow up with patients in her clinic.

The Medical Consultant asks a different resident if she now utilizes her knowledge about programs to share with families before making a referral for them. She replied,

> Absolutely, and they [families] have a sense of... I don't know... security, confidence. They're like, well...the doctor, she knows what she is talking about. ...and I can almost anticipate...you know, letting them know what the process is going to be like.

Another resident has changed what he does before making the referral. After observing an audiology evaluation, a resident states,

> I would still do the referral based on the need of the child, but what would be different is that I would... I assumed there was a physician there as far as doing the maintenance work and there really isn't anyone there. So, I would make sure that I had clearly looked at the child beforehand. It would be nice to make sure the ears were cleaned before. I would love to see the patient before I send them now.

Knowledge of the different resources and knowing how to utilize them is essential for families with children with disabilities. This next resident indirectly says that she is utilizing different resources to support her patients and their families:

> I am happy that I know about Birth to Three because I know which kids are...I know that I should be referring kids, and I know that even if it's a referral that is declined for services it's still a worthwhile thing to do, and that makes me happy. And I'm glad that I know about the project Dr. Dworkin is doing as another alternative...Child Serve...if Birth to Three is not an appropriate referral. I just think that it's better, especially in our patient population and the side of referring and the side of trying to hook up parents into a support network.

Residents are demonstrating their ability to be family centered. As a result of the curriculum, the Medical Consultant shares, the resident is better able to see "things" from the child and family's perspective. She asks more questions, more detailed questions of all patients, but especially those with definite or possible disabilities. She honors the racial, ethnic, cultural, and socioeconomic diversity of families when she consciously has become more sensitive to family's needs (cultural, financial, etc.). Another resident feels that families need to be empowered and assertive. While a different resident is more sensitive to disabled patients whenever she interacts with them. As these points are all very important to supporting families, so is the understanding and incorporating the developmental needs of infants, children, and adolescents, and their families into health care systems. A resident supports this family centered care principle when she stated,

> I am *always* asking the parents of my kids with disabilities how are they doing? Socially? Emotionally? At work? With day care? And filling out forms for daycare and taking a much more proactive role in the non-medical needs of those kids.

One resident talks about his experience in the Family Centered Care didactic session and how he will change his behavior to accommodate the need for follow-up.

> I think just in general from the discussions everybody seemed to emphasize the importance of follow-up and just always just staying in contact with them. Don't let them feel like they're doing it alone, that they come to the office and there's one visit and that's it. If there's certain situations that you need to call them back and say, 'How are things going? Just wanted to check back with you.' I think that one little phone call, a couple of minutes out of your day, makes a big difference in taking care of the patients.

Some residents have altered their examinations in some way. For one resident, his newly gained knowledge has affected what he does when he assesses the child's adaptive equipment needs,

> I can appreciate what goes on there [Adaptive Equipment Specialty Clinic]. I mean I think I have a better understanding, and I guess with having that better understanding, I'll be able to write a little bit better instructions on what I think the child needs.

He also refers to his home visit with an early intervention provider and how he learned new ways to guide parents and what to share with them in examinations.

> The other thing that I found that was very helpful was when I went out on the early intervention clinic visit with the speech pathologist. Just I'm finding in our population there are a lot of children who have speech difficulty and speech development problems, delayed development, and just it was nice to discuss with her some of the signs and some of the things that we can do as far as early screening that they feel might be more effective, and just on how to give anticipatory guidance about developing speech, what types of things to have the parents sit down and do with the children, what types of things to read to them and how to do it.

He goes in more detail and explains,

> When I'm talking with the parents about just anticipatory guidance about cognition and speech [?], but to sit down and not just read a book from cover to cover, but to describe what they see in a book and read it with some inflection. What's this?

> What's that? What color is this? What is this animal sound...what sound does it make? Just altering what they do so it's not one set monotonous.

A different resident will alter her examination by being more in tuned now that she knows what she can be listening for, in terms of speech delay. She will "ask more questions and try to get a handle on how the child is actually speaking" and "spend more time... more time trying to, you know, listen for the child's words."

The Medical Consultant explains that the experiences that one resident has had has made him more able to examine these children, he is not so put off by orthotics or other assistive devices. While another resident explains she will be less aggressive in attempting to feed an infant with clear oral aversion, as she feels that by pushing the oral feeding, the aversion will worsen of the long term. She learned this from a mom that had an infant with clear oral aversion.

Interestingly, a resident observed alternative therapy, music therapy, at a home visit. He seemed skeptical at first to change his own behavior:

> Yeah, I mean I might recommend something like that. I mean I did see a difference in her. I mean I think I'd need a little more evidence... you know, I'd have to see if work a little more before I'd be more comfortable in recommending it to everybody. But, certainly everyone relaxes when they hear music that they appreciate whether it's rock versus classical versus whatever.

After the resident remembered his own experience with a child who would not eat well and then did eat with the "right" music, he responded, "...and he ate really well. So, that made a big difference for us. So, maybe I will try it with one of these parents."

Type of Learning

Many residents have often expressed that learning in a didactic experience is fine but they really understand it and grasp the concept when they see it or can do it. Only one resident actually signified this in the debriefing session when she said, "I just think that I'm an experiential learner and I know that. I learn by seeing and doing and hands-on and interacting with parents, with patients." This is an essential point when developing a training program.

Feedback on Orientation

One resident gave feedback on the orientation session that she was given. During the session, the rotation is discussed in full detail, including such things as goals of the program, visits, paperwork, and contacts. The program runs all three years of the residency, it is hard to get a grasp on everything in the first day. The resident describes this,

> So, it was nice. We went through it. I got a pretty good sense of what was going on, but again it's hard to be oriented when you really don't know what

> the next steps are going to be. It's kind of like being oriented to going…
>
> Medical Consultant: "To residency."
>
> Yes. This is sort of what you're going to do, but you've got to just jump in and do it before you have a good understanding.

And that is what the residents do. They begin immediately with the first didactic session and go straight into the community with families.

Length of Didactic Session

Two residents commented on the length of the didactic session. They both felt that the sessions are too lengthy. They seem to get saturated with information early on and then didn't absorb the rest of the information, thus, viewing most of the session as a waste of time. One resident states, "It was like two hours, two and a half." The Medical Consultant asks him, "How was that in terms of length, in terms of…" He replied, "Horrible." He went on to say,

> We could've done that session [Roles of the Professional and Team Based Models of Assessment didactic session] in probably half an hour to forty-five minutes. And I would've, and it would have been probably more valuable, and I would've probably remembered a lot more if it was shorter.

This resident goes as far to say, "I would say no didactic, or if…just to present what's going on and what's going to come up, half-hour." This would not be possible unless the resident read the material independently and brought back their questions. Unfortunately, there are many residents who would not do this reading and thus, the rotation would not succeed.

The other resident felt that the orientation session, in terms of length, was fine. She states, "The orientation was fine because she basically took less than an hour, which is nice, and briefly went through the book just sort of highlighting the important points." But she feels that the didactic session was far too long. She explains, "I know that I don't get three to four hours worth of information out of a three to four hour session," and "I feel like there are some things that I am forced to go through where the benefits sort of don't outweigh the cost of the time." She presents a solution:

> You know, give us free lunch, have all the interns together, just an orientation of the family-centered module, and then it would actually be better because then they would only need to grab us for one or two hours, not an entire afternoon. I can sit through one or two hours. It's the three and four hours that kill you.

This solution would be a nice one, if it was possible to get all of the interns together at once *and* guarantee that they would always need the didactic sessions at the same time. If one resident is sick or had a visit that was cancelled for some reason, then they would be falling behind in visits but keeping up in didactic sessions. This would not be an ideal situation in terms of learning. The solution should be still be considered; it may need to be altered slightly to make it work.

Feedback on Didactic Session

The residents gave clear feedback about the didactic sessions. They expressed opinions on the videos that were used in the sessions, learning about the history of different fields, case studies, and participants in the session.

Residents have expressed dislike and disinterest in the videos that were presented. One resident states, "They had a video on Family Centered Care. I didn't think that that was really particularly useful for me." This was the same feedback we received in a "feedback session" of all of the residents and hence, have stopped using the videos in the session. Residents are now given a choice if they would like to see them.

Some of the residents feel it is useful to know how the fields of early intervention and special education have changed and they can see how far the fields have come. They said things like, "Yeah, I liked it (historical perspective). Because it gave me an idea on how they're changing," and "It was interesting to learn about the history of early intervention." When asked by the Medical Consultant, "As somebody who is doing primary care, do you find that a useful thing to know the history?" the resident replied, "Yes." Another resident felt that learning about the historical perspective was very practical for her. She states, "I need to understand the history of it. I need to understand how it evolved, what has been done and what hasn't been done, what things...you know, how quickly they're moving and where they're heading to. I think it's very important, and if I want to be an effective advocate for my patients."

Residents have expressed that they have "learned a lot." The information has been "very helpful for her families." Other residents have commented, "I mean, just the information was useful, and to give us the information written down so we can go back and look at it later is useful." While someone else said, "Didactic sessions are going pretty well, actually point some aspects that I did not know prior to starting pediatrics. So that's pretty interesting." She goes on to say,

> And it [Special Education didactic session] was good. A lot of things were reinforced from the early intervention and from the family visit and Birth to Three. That was in the beginning it was reinforced, and put a perspective on what special ed. actually is and what acts – the IDEA act and everything else that goes into play. So, that was pretty good.

One resident felt that the case studies in Roles of the Professional and Team Based Models of Assessment didactic session were redundant. He says, "I think they tried to go over specific scenarios. Which I didn't find very useful, because, I mean, I could figure that out, you know, by reading it but it's a lot of redundancy." He goes on, "You know, they're going to have speech, but what is the speech person going to do? You know, it was sort of superficial, which I could get, but the role and the actual process of what they were going to do seemed to be skimmed over." He does not feel that the didactic sessions are "valuable."

Some of the residents did not mind having didactic sessions with only the Project Coordinator, while others thought that the one on one was difficult for learning. One resident told the Medical Consultant that having the Early Intervention didactic session, alone with the Project Coordinator, was a positive experience which will help her in caring for her families. Another resident felt that the format was good (one on one) and the information was enlightening. A third resident felt that the sessions were good, even if it was just one resident and one facilitator, but they preferred participants from different disciplines to join the group.

A different resident felt just the opposite. She did not like the one on one when it occurred and preferred to always have other participants. She expressed this very clearly when she states, "The didactics in general need to be overhauled. They need a lot of improvement because it's very difficult to have a didactic session be one-on-one." Later in the session, she says, "I think that with significant restructuring, the didactic session has the potential to be one that is extremely worthwhile."

Participants

The participants in both the didactic sessions and the community visits have really added an unique dynamic to the program. They include children with special needs, parents of children with special needs, providers who work with children with special needs and their families and sometimes, other residents. The residents have enjoyed their participation and have learned from them. One resident speaks about the Family Centered Care didactic session that she had in which there was a panel of parents available. She states,

> So, she (Molly Cole from the Family Center) was wonderful, and she obviously has a lot of neat stories and to sum up that experience: it is parents who are very frustrated with the medical system expressing their frustrations and anger and disappointments in the medical system and talking about what it's like to live at home with a child with special needs... and how their perspectives have changed. I believe it was a worthwhile experience. It was nice to have the input of three different parents as well as Molly.

Important to note though, this resident felt that it was not as optimal a learning environment because she was the only resident with 4 parents. She would have preferred to have another resident there also to take the attention off of her. She says,

> However, again, it's just difficult to do that when I'm the only intern. Even to have one or two others with myself would make it, I think, just an opportunity where I'd feel less like I'm the center of attention. So, it's not the optimal learning environment, and when its three-on-one, frankly, really the only thing that I'm getting out of it is the opportunity to listen. There's no real constructive opportunities for me to contribute to the conversation, except to emphasize with

> them for the way these doctors rile them, and that's an awkward role for me to be in.

Less participants would have given her the opportunity to contribute more. This needs to be considered when planning the sessions.

Other residents have shared her views when he said the he would like to have professionals in the sessions, but, "I don't think that five professionals there... you know, I don't think that would be valuable." It would be too much all at once. This resident was referring specifically to the Roles of the Professional and Team Based Models of Assessment didactic session.

Another resident speaks about her Family Centered Care didactic session: "There were a couple of parents actually, which was really nice. You know, you could get their point of view."

"I think I had one other resident with me, possibly two, for the early intervention didactic." Having residents together in didactic sessions has been requested by most residents. Unfortunately, due to scheduling difficulties, this is not always possible. It is always considered when scheduling.

One resident gained a lot from visiting a mom and her child in their home. He states, "And then I met with... did you meet Jennifer? Is that her name? She's a nurse at the NICU at UConn. So, it was a nice perspective to see how she's dealing with things...But, meeting her, seeing what she's been battling with and seeing her perspective on everything is just amazing."

A different resident interacted with the child with disabilities that was included in the daycare that she observed at. She says,

> No, I interacted with the child. Yeah, I didn't observe. Because I thought that maybe sitting down with the children in a group would get more of an integration as opposed to just standing up and watching them. I just felt that maybe the other children saw me sitting next to her and playing only with her. I tried to include the other children, but it was obvious that I was sitting with, you know... so I felt that maybe... they felt that I was there just for her.

One resident felt that including a physician as a participant in the program would be a good idea. She says, "If it was in lieu of, and not extra time on top of the session, and it was a part of it. I think even 15 minutes to a half an hour with a pediatrician certainly has the opportunity to be very helpful." This program is going to have a pediatrician working with the residents, directly, during community visits and didactic sessions, beginning in July of 1999.

Perceived Attitude of Facilitators

One resident perceived the facilitators as possibly over zealous in making their points. He states,

> We're constantly being hit over the head, that, you know you should keep this big world view, and that you know, which I hope I have to some degree.

> It's like you're constantly being reminded that. It's like, I sort of figure that it's propaganda, you know. It's like, they're trying to tell you how to think about things, and, which I guess they have their own agenda and that's good, but, you know, I don't want to be constantly reminded about that.

He goes on to say,

> ...but it just seemed like she was saying, you know, the whole medical profession needs to change, the whole, you know. I kept...I just felt like, you know, I know not to treat patients like that. And that's what I got as far as adversarial. Like they were trying to tell me 'you need to change your view,' when they didn't really know my view.

Written Material

Residents had varying views on the written material. Some felt it was a good resource while others felt it was too big and inaccessible. One resident had a lot to say when it came to the written material, she stresses that "this book is just not an accessible source of information." She goes on to say,

> Then the book itself is too big. I already e-mailed [the Project Coordinator] about this and she said she would try and make them double-sided and simplify ...So, that's just not practical. It's not accessible information and it's not practical. And everything is double-spaced and it is just not concise. I would prefer outline format. I would prefer concise. One notebook for all of children with disabilities, I think is a reasonable amount of space on my bookshelf.

She suggests,

> But maybe one [laminated sheet or pamphlet] for physicians. You know, Step 1, J, call 545- whatever the number is. Step 2, you're going to refer, you need this information about your patient to make this referral. Step 3, you know, family-centered care will call your patient and set up an appointment and then send you a letter telling you what goes on, OR, you know Step 4, you then need to call your patient. Just tell me boom, boom, boom, boom – what's going to happen, in what order, how's it going to happen, and what are the roles that I need to do to make it happen. *That* would be very valuable information, and that is not something that you can just tell me. That you have to write down and put it in a format where I can stick it in my continuity clinic binder and I can have it when I need it because otherwise I'll forget.

When this resident is asked about the law section in the material, she again is concerned with the amount of information. She says, "Again, material presented in such a way that it's not... it's not the actual source. It's sort of a summarization of the law, which is again, not helpful to me. It's like reading an encyclopedia instead of the actual." She would prefer the actual law,

> Even though law is like sort of pain to go through. If I'm ever going to go look it up, it's because I'm going to want to define [something]. So, you can give me a couple of copies of the law if it's important to you, or again, a very brief summary of the history, but, you know, an 80 page notebook is not acceptable information.

However, another resident commented on the law being confusing. The language in the didactics is often difficult.

A different resident feels that there is too much repetitive information in the didactic material, he expresses this when he says,

> I just find very, very few uses for it. I mean, again, it's like those scenarios [in Roles of the Professional and Team Based Models of Assessment] I was talking about. There's so many and there are just very subtle changes in them, where I think they can be all consolidated. And a lot of the written material can be consolidated I think.

He goes on to state,

> I would almost bet that most of the house staff never reads that, after we read it in the didactic. I mean, I know I never read it again. I would almost bet that most of the house staff never reads that, after we read it in the didactic. I mean, I know I never read it again.

Contrary to his believe, other residents have found the information useful and have utilized the written material as a reference. One second year resident explains, "It's all... as a reference, I think that's the best bet to use a reference. I'm reading it prior to each disabled visit, but not in any means memorizing it. I don't think it's meant to be memorized anyway." A first year resident also shares this view, "I mean, just the information was useful, and to give us the information written down so we can go back and look at it later is useful..."

Only one resident commented specifically on the orientation manual; she liked it, "...it was nice."

The evaluation forms, also part of the written material, were only commented on by two residents. Both are second year residents. One feels that the forms are "brutal"; they are too long. The other resident commented specifically on the preceptor forms. She does not feel that these forms accurately assess the resident since the resident-preceptor interaction is sometimes passive (observation). She also feels uncomfortable asking the parents of her patient to fill out the preceptor form for the home visit. Over the past months, the debriefing of the resident by the preceptor has been addressed by the Project Coordinator at the different community sites. The resident-preceptor interaction has been increased, even if the actual visit is observational. This program will soon have a pediatrician attending visits with the residents, which will also greatly increase this interaction.

Feedback on and Usefulness of Community Visits

Residents have given feedback on different aspects of the community visits. Some have discussed overall purpose of the visits, while others spoke of certain, particular visits. In addition, many have commented on the usefulness (or not) of community visits.

One resident described the community visits as "field trips," he loves them! Another resident tells us, "I personally like visits." The Medical Consultant states that for one resident the home visits, including the one to a program family's home, their own continuity clinic patient's home, and the home visit with the Birth to Three provider were all high points for her.

One resident felt that the program would like him to have the big picture and generalize the information about speech therapy instead of concentrating on particulars. He does not feel that this is a positive thing. He states, "However, I think the downside to that visit was... what they wanted me to get out of it. Judging by the paperwork, it's like they want you to get this whole world view about what a speech therapist does, rather than just concentrating on how to talk good to the kid."

Other residents commented on specific sites that they visited, including Birth to Three visits. One resident called the early intervention home-based visit enlightening and educational. While another resident also commented on this visit, expressing that it was good to see what the speech therapists do. Still a third resident felt that seeing a child with Down Syndrome receiving Birth to Three in the home was excellent and observing early intervention services in an urban setting for the early intervention program visit, was also excellent (she specifically stated the names of the sites that she liked). A fourth resident speaks about his learning experience at a early intervention home-based visit,

> The other thing that I found that was very helpful was when I just out on the early intervention clinic visit with the speech pathologist. Just I'm finding in our population there are a lot of children who have speech difficulty and speech development problems, delayed development, and just it was nice to discuss with her some of the signs and some of the things that we can do as far as early screening that they feel might be more effective, and just on how to give anticipatory guidance about developing speech, what types of things to have the parents sit down and do with the children, what types of things to read to them and how to do it...That was <u>very</u> practical.

Lastly, a fifth resident thought that the exposure to Birth to Three and their work was a good thing; she states, "...she had pretty profound deficit, and it was good to see what they [Birth to Three providers] actually do because, you know, for people. So, it's kind of nice to see what they're actually doing for these children."

One resident thought that a barrier to the gaining knowledge at the early intervention home-based visit was that she did not know the family. She explains,

> I find it very difficult to go into a home and off of that start asking medical

> questions about their child. I feel that it's intrusive. At the end of the visit after I've established a rapport, I'm must less hesitant to ask about what's going on. I was lucky the physical therapist brought a copy of his IFSP, and so it was like his individualized family service plan, so it showed the long term and the short term goals that they were working towards as a part of early intervention.

The thoroughness of the preceptor, a physical therapist, allowed the resident to gain more information without feeling as if she was being intrusive. This is an important point.

One resident commented that a particular elementary school really embraced inclusion, from the principal down. She recommended that every resident have a chance to visit this particular school.

One resident made a blanket statement regarding the topics of special education and early intervention: "I would say it's useful. I would definitely say it's useful." Another resident felt extremely comfortable addressing a problem in a patient's school because she knew the law and therefore knew that patient was eligible for continued services. She used this information to advocate for continued services for her patient (and got them!). This information was extremely useful to her.

Many of the residents had feedback to share on the home visits, primarily positive feedback. For example, one resident tells us that, "I think the home visits are a great piece of the puzzle," while another says, "I think the home visits are crucial. I think they're important." Others have spoke directly about the families they visited and responses were, "excellent visit," "extremely informative," and "useful." One resident found the home visit useful because the mom, "...was able to give me a couple of stories that were... really hit home, so for me it was useful." A resident felt that her home visit was excellent overall. The resident shared with the Medical Consultant that the mom was extremely knowledgeable about the services available for her child and how to access them. She was extremely open about what has worked and what hasn't. A first year resident exemplifies the home visit and why it is so useful. She states,

> That (home visit) was wonderful. I can't speak highly enough about the home visit. It was the antithesis of the didactic session. It was a *real* opportunity to go into a real family and a real home where you get to see the environment in which the child lives. You get to see the changes that have been made in the environment in which the child lives and how the parents have responded to it. I lucked out. I was lucky enough to meet with a woman, Jennifer Joy I believe her name is, who is very much an advocate for her child. Her child has a disorder that is unnamed, and he has a lot of central hypotonia, and she just has done everything she can to advocate for him. She is a nurse by training, and their living room has been transformed to tools of physical therapy. And, you know, she's been able to find babysitters and trying to get him into day care.

Another resident was initially uneasy about asking and going to her continuity clinic patient's home (five-year-old former preemie). She felt she would be an unwanted intruder that did not belong in their home. She did in fact conduct the visit and commented afterward that she felt that she could now understand the family structure, their needs and concerns much better, and has a much more realistic appreciation of the role this child plays in the parent's life.

One resident does not feel that the curriculum in Family Centered Care module has changed his approach to families' needs, i.e. cultural, ethnic, religious, but in being more informed about the services, he can be more helpful to his patients.

Two residents gave feedback on the NICU Follow-Up Specialty Clinic visit (from the Early Intervention module). One made a suggestion that residents do not visit this clinic until after they have had at least one rotation in the NICU so that they have a real sense of where these children and families came from. Terrific suggestion. The Project Coordinator has been instituting this rule ever since this debriefing. The other resident didn't gain from the NICU Follow-Up visit. She felt that she gets more out of speaking to the parents in the actual NICU. She explains,

> I don't think I got a whole lot out of that (NICU f/u visit), and I think probably I've gotten more out of talking to some of the parents that I see who I met in the NICUs that are now on the floors. The family I spoke to in the NICU follow-up clinic, their child is being discharged from the clinic, you know, an older preemie who has done very well, really wasn't having any problems at all. So, they were thrilled and happy, and so they came once to the NICU follow-up clinic and they weren't going to come back any more. So, it really wasn't very... well, I mean it was interesting to see how they dealt with taking baby home but the child wasn't on any medication, they didn't have to learn how to do G-tube feedings or anything like that, so it wasn't quite the same.

She goes on to say, "I think all in all we see so many families from our own NICU experience that we can get the NICU follow-up... I mean, just to talk to the families and find out how that transition went."

Two different second year residents spoke of the usefulness of observing in both the Rehabilitation Department and the Speech and Audiology Department. One resident thought her visit was "real neat." She says, "They had students, physical therapy students, and occupational therapy students that day and had the [professionals] come there doing the actual PT, and it was great." The other resident feels that his visit to the Speech and Audiology Department was useful because now he knows, "what to expect, most definitely. What kind of environment they're going to be in, how much responsibility the parent actually has in trying to set this up as far as setting up the child... though definitely because I know what to expect." He tells the Medical Consultant that learning about different specialists is a worthwhile experience.

Realities of the System

Residents have shared that they have learned a lot about how things can go for children with disabilities and their families. They are really getting a sense of the reality of life for these families. One resident went on a home visit to her patient's home and saw first hand how difficult it can be to show up for appointments (transportation) or call if there is a problem (no phone, no English). Her thoughts regarding compliance have changed since that day. Another resident realized after speaking with a family on a home visit, "How they [families with children with disabilities or special health care needs] fight for everything. And it shouldn't be that way. It shouldn't be that you have to fight for something so simple...as a chair for your child." Still another resident that visited a school and spoke with the staff there heard about the issues of poor communication with the physicians; the teachers noted issues of parents as the "middlemen" in information transfers. Lastly, one person spoke about inclusion at a daycare and how best practice existed in a more affluent area but not in the poorer area. She explains,

> But, I don't know, in a sense, there was also like bias – is that how you deal?
> Is it because it's West Hartford and it's not downtown Hartford? So guaranteed,
> go 6-7 blocks past Prospect Avenue, and you're not going to get that, you know,
> in 20% of the classroom [with special needs]...

Contacts in the Community

Residents are making contacts in the community. Both examples that emerge from the debriefing session transcriptions are regarding Birth to Three. One resident now knows some of the providers, including the Director, of the Birth to Three program that primarily serves her clinic of patients. She tells the Medical Consultant that, "When I make the phone call, I know the place is there. Receiving the information, I actually know a couple of the people by name." She goes on to say, "I've even become friends with J. B. [the Director of the Birth to Three program in her area]." Another resident says, "I had someone turned down from Birth to Three and yet they still did a developmental follow-up, which has been great. Parents love it. I enjoy... I get a nice handout from them about all the information." These programs keep the contact between the provider and the pediatrician going by sending reports, this helps with not only collaboration, but with continuity of care.

Continuity of Care

We see residents being able to keep some continuity in their clinic and in their other rotations. One resident keeps vigil on her patient's Birth to Three services and is involved in his transition process to the school system. Another resident referred a child to Birth to Three, has seen them back in clinic, and says the family are, "very happy with the services." Two different residents have seen patients that they worked with on the inpatient ward in the hospital in different settings for this rotation. One resident "actually saw a patient there [Hospital For Special Care] that I sent there. It was kind of exciting." He was then able to see how he was doing in this new setting and see what the new program was doing for him. The other resident saw a patient in the Neurology Specialty Clinic Visit for this rotation that she had admitted to the impatient ward at Connecticut Children's Medical Center on a prior rotation. This child had Meningococcal Meningitis. She was astounded to see this child had few residual disabilities from the Meningitis.

Feedback on Evening Seminars

Only one resident chose to speak about the evening seminars. She said, "I went to the two (evening seminars) that were prior and those were excellent."

Feedback in General on Curriculum

Residents, in general, value this curriculum and feel that it will make them better pediatricians. One residents tells the Medical Consultant,

> I am very proud and happy to say that this curriculum has made me a better person and a better resident, to help my patients in difficult situations, to help the family -- not just the patient but the entire family – and that I feel that other residency programs really need to get on the ball and start similar curriculums for their residents because it's greatly needed.

Another resident shares, "I recognize that I'm lucky to have the opportunity to learn about this, and I think it will make me a better pediatrician when I'm done."

A different resident recognizes that without this curriculum, it would be difficult to obtain the information on her own. She explains, "but just to get a familiarity with it and what's out there as far as accessibility and how to get information for a patient and family would be easier than trying to do it on your own."

The Medical Consultant explains that one resident (different from above) is "generally satisfied with content and relevance" of this rotation and that another resident "loves this curriculum, especially home visits and placements." A third year resident has taken from this curriculum, skills that are crucial for him to learn in order to do emergency medicine successfully. "These skills are (1) the ability to examine patients in wheelchairs (2) improved communication with patients and families, and (3) the ability to see patient's problems from family perspective," says, the Medical Consultant. She also said, the disabilities rotation is assisting in the overall goal of residency as one resident is "incorporating all that she has learned through didactics, visits, and observation into her daily medical management, not to her disabled patients/families only" and

> ...she is better able to see 'things' from the child and family's perspective. She asks more questions, more detailed questions of all patients, but especially those with definite or possible disabilities.

Some residents have generalized this information and the knowledge learned in this rotation to apply with many different families. To one resident, "this [disabilities rotation] has made the difference in terms that I understand the whole process and I feel very good about getting feedback, about the family getting the actual services that they need." A second year resident states,

> So, how would I take that home to my practice? Just the concerns of the family members. It goes beyond patient care. It goes beyond medical issues. It goes beyond the normal otitis and the strep. You know, there's a lot more issues underlying once they leave your office, and what's available to them and how could we access it easier and make their life a little easier lifestyle... for the parent as well as for the child.

Prior Experience and Knowledge

Some residents came into this rotation with prior experience and/or knowledge about children with special needs and/or services available for them. Although all of the residents filled out a "Prior Experience" survey, some of them included information on this in the debriefing sessions. Some of the prior knowledge topics included, Birth to Three ("I had experience with Birth to Three before I even came in"), cultural sensitivity (resident worked for a large company in the minority hiring division), and law ("Although when we learned about the laws initially, I had some knowledge about that"). One resident, although he had no formal training on children with disabilities, followed an infant in the home for approximately 6 months on a weekly basis as a medical student. This child had a chromosome anomaly syndrome with associated developmental disabilities. The experience allowed him to see first-hand the impact a child with a disability has on the family. Another resident, although had no information on transdisciplinary teams, knew that the teams he was involved in were not good examples. He states,

> That's really the only team that I'm really exposed to and that's more of a hierarchy. You know, it's like we're at the bottom and you know, the attendee's battle, and you say 'go ahead'. I think it's a good example of what not to do actually. You know, and I think...but again, I think I already knew that before being told what the teams are.

Exposure

Residents have been exposed to many different things that they may have not had the chance to see if not through this rotation. For example, residents have encountered family life for families that have children with disabilities, premature infants after they have left the NICU, transitions from Birth to Three to the school system, pull-out therapy versus home-based therapy, and much more. It seems they would benefit from these experiences; many commented on these different exposures.

Residents were exposed to families with children with disabilities. Two residents spoke on this topic. One said, after being asked if there was anything about the visit that she would carry away with her,

> There's a lot about the visit. How a family interacts with the children. What

> their lifestyle is like outside of your office. When they go home, what do they do. And that you never see, you know, on a personal basis you never see that. How many things that we take for granted is such a tremendous act for them. You know, getting up and getting dressed, getting the kids just eating is a major effort, where we don't even think of that normally.

She goes on, "I just saw what they (family with children with disabilities) do and their lifestyle." The other resident was exposed to more than just a family's life style. She shares this information,

> That was wonderful. I can't speak highly enough about the home visit. It was the antithesis of the didactic session. It was a *real* opportunity to go into a real family and a real home where you get to see the environment in which the child lives. You get to see the changes that have been made in the environment in which the child lives and how the parents have responded to it. I lucked out. I was lucky enough to meet with a woman, J. J., I believe her name is, who is very much an advocate for her child. Her child has a disorder that is unnamed, and he has a lot of central hypotonia, and she just has done everything she can to advocate for him. She is a nurse by training, and their living room has been transformed to tools of physical therapy. And, you know, she's been able to find babysitters and trying to get him into day care.

Another resident was exposed to a different perspective on the medical community…a family's. She also had a chance to speak with a mom about her hopes for her child's future.

Some residents have been exposed to different aspects of early intervention. One resident was, "…able to see the transition from the point of the referral to the actual intervention, and getting the feedback from the family." While another resident saw Birth to Three services in a home based setting for an infant with developmental delays; a yet a different resident observed these services provided for a child with Down Syndrome. A fourth resident explains, "I saw the team working together, I loved it because they're with the child in his home."

One resident thought, "it's very nice to see that preemies do just fine." This is not usually the resident's experience, since they tend to work with children that were premature or are premature while they are sick and in the hospital.

As physicians, these people may hear about different "needed" pieces of equipment, but one resident actually got to see some of it. She says,

> I got to see (at EI home visit) some interesting pieces of equipment - a stander, a bush chair - and watch the different ways that they were trying to create alternative means of communication for him and more, especially fine motor skills so that he could use his hands again ultimately so he can communicate and be a little bit more self-reliant as far as self feeding.

Five residents have commented on their experience in community based natural environments for children from birth to three. One of these residents explains,

> And it's interesting to note that they, in this particular group at the F. C. C., that they are using that inclusion. They're not doing the 50-50 and that kind of ratio, that percentage, - which is great for the children with disabilities because they've seen how children without disabilities are acting and how they're playing and how they're developing so that might be something for them to strive to or see how the interaction is. So that was great - that it actually is carried out.

A different resident observed a child with severe visual loss and the acceptance of the child by other children in an inclusive day care. While another resident observed early intervention in a day care situated in an urban environment.

While some residents observed inclusion and natural environments at the birth to three age group, some also observed inclusion at the school aged group. One resident commented to the Medical Consultant on his exposure to the range of placements available for children with special needs in the school system. A different resident saw two different methods to therapy. She says, "I saw the contrast when I went to an A. program where, in a classroom…where the speech therapy person kind of pulls the kids out, and she has her own individual goals and how to approach that child. And then, as I said, I saw the other at home working together [as a team]."

A resident spoke about different therapies. He was able to learn new information regarding alternative therapy at a home visit. He talks about his experience,

> Other things that she [mom] tries like music therapy seems to work, and K responds to it and when she would put on certain music K would calm down and just kind of settle out and be more receptive to feeding and then she'd switch it to different music and you'd see a difference in her behavior.

He goes on to discuss the other alternative therapy he was able to observe, acupuncture done with lasers. He says that mom believes it works for her child. He states,

> I think a lot of that going into those complimentary therapies or alternative therapies is because of a frustration in dealing with, you know, the allopathic medicine, and so I got a chance to see how she funnels some of that frustration into what she thinks is more productive for her child.

While this resident was exposed to alternative therapy, another placed high importance on his exposure to speech therapy. He states, "But it was good to see the process. I think that was valuable... what actually takes place during a speech. You know, it was good, it was good."

Many residents were exposed to new equipment, technique, and even great recoveries in specialty clinics. In the specialty clinic, Adaptive Equipment, one resident had commented on learning about fittings (for wheelchairs), insurance reimbursement, and cost of adaptive equipment. We are told by some else that this clinic was, "...much more involved than I expected it to be." He goes on into detail,

> Well, there were definitely some within the fittings when they saw them, then molds and when they were evaluating how they fit, there were areas that were potential pressure points. For instance, one girl because of her contractures would basically abduct her right knee into some of the bars, and so they had to rework how she sits, raising her chair platform up a little bit higher so that the knee wouldn't hit that specific point and that's emphatic.

He goes on to talk about how the team includes the parent,

> I think someone from the wheelchair company, then the person who does the molding, and those two generally work together with a lot of the technical and they like kind of supervised the... but all three of them brought the family into it. And with every aspect, if they were going to, for instance, with that child where they had to raise the chair, they said, 'Dad, is this okay? I mean, you have to raise this child in and out of this seat. Does this make it easier or harder for you?' And so, had the family input with that and not just made modifications for the sake of making it, but also wanted to make sure it was practical.

One resident saw that "positioning" in NICU has long-term implications for gait development when she visited the NICU Follow-Up Clinic. Another resident was exposed to the Hospital For Special Care. This is an intermediate facility that many residents send children to or care for children that have come from there. One resident tells us how his exposure to this facility was valuable:

> I've sent kids to the Hospital for Special Care. So again, it was a very valuable experience to know what goes on there and what, you know, what their philosophy is, and I thought it was very, very valuable.

Lastly, a resident was exposed to a "nice recovery" in the Neurology Specialty Clinic. She saw a patient for follow-up with meningococcal meningitis. This child had been on the impatient ward when the resident was working a while back. This resident was exposed to an astounding recovery this child had, with few residual disabilities from the meningitis.

Barriers

There were barriers to the rotation and to practice noted. Barriers to the rotation included, Friday sessions, post-call, small amounts of time in each placement and the availability of preceptors at placements. Barriers to practice were simply language and money.

One of the residents commented on Friday sessions. On Fridays, the residents have a mandatory 7:30 – 8:30 am meeting and then Case Management (also mandatory) at 12:00 to 1:00 PM. This limits the residents in time when out on community visits. More than one resident shared this feedback:

> Yeah. I mean, I was kind of frustrated with that because it felt very rushed. It was a Friday morning, after the resident lecture but before case management, so I only had like two hours actually to spend with the therapist. It was rushed. So I only saw one visit with one family. And I would've kind of just liked to have like more time to try to go see her with another family...Friday mornings aren't good.

Other residents have talked about being post call as a barrier to their learning. One resident remembers "being very tired," while another clearly states,

> Everyone's sort of staring at you, looking for feedback. If you're post call, you're falling asleep and that's not... I feel embarrassed and I feel like I'm being rude to the people who are taking time out of their busy schedules to help me.

One resident makes the point that each resident only sees each "activity" for one ½ day and maybe that isn't enough for him. He states, "We're only seeing a very small snippet of time, and we're not... maybe not having our questions answered as far as other things that we see. You know, like you said, 'I see this kid with this' that I didn't see at the visit."

Another resident brings up an important point about the barrier it causes to the learning process when there isn't enough staff or preceptors at the community visit. She explains,

> But the principal or whatever of the program wasn't available at 12 o'clock. So, I just left the paper, the evaluation, on the desk. They told me just leave it on the desk if she's not there and go. Well, I get this horrible... feedback. I never met the person who filled out the form...They were short staffed. They weren't... not that they couldn't answer my questions, they weren't available to answer my questions, and then it seemed like when I was leaving there was no one around to wrap things up. And it just wasn't a good visit. And then also I thought that maybe it'd be more of... I guess they were waiting for me to ask questions than them pointing them out. And when I started to do that, they just seemed really busy. So, it just didn't go as smoothly as I thought it would.

Barriers to practice have also surfaced. Three residents speak about the language barrier. One explains to the Medical Consultant that he feels that the patient's language barrier may interfere with an accurate developmental assessment. While another resident also worries about the accuracy of the developmental assessment, "I mean, it's hard to ask parents about that, especially if there's a language barrier and it's their first child." The third resident talks about a family who is fighting this barrier, "And there's a language barrier because they are primarily Spanish speaking, but they have really learned who to call when they need to get their point across."

Lastly, a resident sees injustice in the system and comments it, "I think it's more monetarily more than anything else. Because I think the resources are there. If it's there for one. If it's there for West Hartford, the resources are there for Hartford. But I think it's just a money issue." She goes on, "Those living in Hartford probably don't have the same income as the people living in West Hartford."

Need

Residents have identified different needs that are particular to their interests and that are general. Some of these needs will be met naturally for the resident as they work their way through the curriculum and some are not currently integrated into the curriculum. For example, one resident would like to observe Occupational Therapy and Physical Therapy, while another wants to see a PPT. These, along with the following, are already in the curriculum: audiology visits and Hospital For Special Care Specialty Clinic visit. Other residents have individual needs/interests that are not unique to the curriculum but can be accommodated, such as a visit to a group home, more specialty clinics, and serial PPT's. The resident states, "I think just sitting through the serial PPT's would be much more beneficial because you would have seen different ways of doing it and different types of families and how either the mothers were very involved or not involved or whatever."

Lastly, some residents explain different needs that could benefit all in the rotation. One woman says,

> Yeah, I mean that might be useful. I think we have a couple of lectures on it… you know, trying to talk to parents or trying to give bad news in a good way so that parents feel like they can go home and they can call you again if they come up with anything.

Another resident points out the need for a medical consultant to be right on the front lines. One resident feels she needs more debriefing, "someone sitting with you and saying 'what did you see' and then discussing what it was in terms of more general stuff. Right, I think that's a good point actually. Especially for this group of visits, I think it would be valuable." Two other residents could use some direction and help identifying children with special needs in their clinic. One resident was frustrated by the process and the other tells us, "It's hard, it was hard at the beginning to sort of use them as people for this…for the disability thing. You know, I always saw them as patients outside of this. Now I think I'm just getting the point to include them into, like going to home visits, you know, for that, so…" A Medical Consultant is beginning in July of 1999 that will have this direct contact with the residents.

A different resident needs more clarification on the goals of each module and how to refer to the Family Center. She explains, "maybe it's because they didn't make their goals or concrete goals as far as what they wanted me to get out of the Family Centered Care module clear enough to me that, you know, I didn't feel like there was tasks that I could accomplish this year." That same resident had other needs: she wished that she could spend time in NICU Follow-Up while she was on her NICU rotation; she feels "a brief paragraph on sort of what is the situation of the place you're going to might be helpful," including the medical condition of the child she would be observing; she would like to review the answers to her pre/post tests; and she would like to have a step by step guide on how to refer your patient to needed services that she could include in her continuity binder.

Future Practice

During the debriefing sessions, future plans are divulged by some residents. Two resident plan on going into primary care, one in New York State. A different resident plans on going into private/general practice with a specialty in allergy while another plans on going into emergency medicine. A second year resident, planning on practicing in Florida, wants,

> ...to establish a network (in Florida). I want to get to know the people who like here in Connecticut I could call if I need to make not just a referral but just a plain question on, you know, making the transition from a Birth to Three to school system. So, I need to really get started with my network.

She's planning ahead!

APPENDIX J

Sample Outreach Meeting Records

Meeting Record

Date: March 23, 1999
People in Attendance:
Jim Loomis
Christy Berr

Issues Discussed:
1. Update on specialty clinics

Summary, accomplishments, recommendations:
We reviewed what social workers have been moved into what clinics. This change of staff occurred last week, I believe.
Jim will call Joanne Stevens and leave her a message about working with me. Joanne and I have never met or worked together. She is new to CCMC. I will call Joanne tomorrow.
We now have connections in almost all of the clinics that support children with special needs. I will continue to try to make connections to two clinics at St. Francis, Sickle Cell and HIV. I will also call about the Hematology/Oncology at CCMC.

Follow Up:
Next meeting:
None

Submitted by: Christy Berr

cc: Dr. Mary Beth Bruder

Meeting Record

Date: September 17, 1998
People in Attendance:
Barbara Dimatio, Pupil Services and Special Education Director for East Granby School System
Christy Berr

Issues Discussed:
1. Physician's Training Project

Summary, accomplishments, recommendations:
Barbara spoke to the teachers and other administrators about this project. They agreed they would like to be involved. We made a date for me to visit this school system. I will bring copies of the forms with me.

Follow Up:
Next meeting:
I will visit this school system on October 9, 1998 at 8:00 am

Submitted by: Christy Berr

cc: Dr. Mary Beth Bruder

Meeting Record

Date: September 15, 1998
In Attendance:
Dr. Patricia O'Connar, Director of Special Education and Pupil Services in Rocky Hill
Christy Berr
Mary Roche

Agenda:
1. Observe classrooms
2. Evaluation Forms
3. Different Visits
4. Directions
5. Contacts

Summary, accomplishments, recommendations:
Dr. O'Connar took me to all of the relevant classrooms in the Steven's Elementary School. I saw both inclusive classrooms and resource rooms. I was introduced to all of teachers and spoke to most of them about the physician's project. I also spoke briefly to the psychologist and physical therapist. One very interesting thing that the teachers in two inclusive classrooms are now instituting is a surround sound system. There are speakers up on the walls and the teacher wears a cordless head set that she speaks into. The children who are hard of hearing are able to be directly involved in all activities this way and do not need one-on-one assistance. The teacher also said she likes it because now she does not have to raise her voice for children sitting in the back of the room. All children are benefitting from this device.

I showed Dr. O'Connar the different forms for the elementary, middle and high school visits. I also discussed all of the possible visits: special educational, observation of PT, OT, and speech therapists, and observations of PPT meetings or team meetings. She felt that the teachers and therapists would like to become involved in all of these visits. We ended our visit in the nurse's office. I explained the program to Mary. She was very excited and offered her assistance. We all decided it would be a nice introduction to the system if the resident spent a few minutes talking to Mary when they first arrive and then move on into the classrooms.

Dr. O'Connar will be the contact for all of the visits. I will have to contact the teachers I had been working independently with in the last school year and let them know this.

We ran out of time. I was unable to secure directions to the high school. I will need to get these at a later date.

Follow-Up:
I will call Dr. O'Connar as soon as I have a resident to visit the school.

Submitted by:
Christy Berr

Cc: Dr. Mary Beth Bruder

Meeting Record

Date: September 15, 1998
In Attendance:
Barbara Draheim
Christy Berr

Agenda:
1. Specialty Clinic Visits

Summary, accomplishments, recommendations:
Barbara is the nurse practitioner in the specialty clinics muscle disease and mylominingocele. She has agreed to be the contact and preceptor of the residents in both of these clinics (since there are no longer social workers in these clinics).

Muscle disease clinic meets the first three Mondays of every month in the PM.
Mylominingocele clinic meets the first three Wednesdays of every month in the PM.

I will drop off forms for her to review before sending a resident to her.

Follow-Up:
Drop off

Submitted by:
Christy Berr

Cc: Dr. Mary Beth Bruder

APPENDIX L

Example Sessions with Legislative Consultant
Legislative Consultant Meeting Records

Examples of Sessions
With the Academy of Pediatrics' Lobbyist

**All of the sessions take place in the Legislative Office Building and/or the Capitol in Hartford.*

#1

Orientation to the process and the upcoming activities, completed by Judy Blei or one of her staff (approximately 15 minutes);

Observe Financial Advisory Committee Meeting, run by the Lieutenant Commissioner;

Reflect on this experience and speak to legislators about the issues that were raised;

Speak to the government relations person for the CT Medical Society, learn about this society's agenda for the legislative session and what they are doing to advocate for the issues at hand;

Observe a press conference given by the Chairman of the Judiciary Committee;

Meet with other legislators regarding issues that the Academy of Pediatrics is advocating for, i.e., how to get pediatricians involved with discussions about smoking with mom's as preventative care for the children;

Debrief the resident about the day's activities.

#2

Orientation to the process and the upcoming activities, completed by Judy Blei or one of her staff (approximately 15 minutes);

Observe the Voices for Connecticut's Children meeting on "Government Accountability and Systems Change";

Observe the Graduate Medical Education Task Force;

Observe the Public Health Committee's public hearing;

Speak to legislators about the issues that were discussed in the public hearing and/or task force meeting, i.e., MATCH (Mobilize Against Tobacco For Children's Health."

Debrief the resident about the day's activities.

Meeting Record

Date: January 4, 1999
In Attendance:
Dr. Mary Beth Bruder
Judy Blei
Christy Berr

Issues Discussed:
1. Evening Seminar
2. Legislative competencies

Summary, accomplishments, recommendations:
Judy will use the gun control issue for the mock public hearing at the evening seminar. This is a big issue for the Academy of Pediatrics this legislative session. Judy will supply the appropriate handouts for this mock hearing and on advocating at the state level. Other issues coming up for the Academy are the tobacco settlement and graduated drivers licensing.

We will contract with Judy so that the residents can spend time with Judy and her staff in order to complete their competencies for The Legislative Process module. They could be orientated to the process for 15 minutes or so, meet with legislators, observe legislative committee meetings, public hearings and/or press conferences, and then be debriefed by Judy or her staff. This could all be done in a 3-4 hour block of time, states Judy. Some of the committees that would interest them would be the Public Health Committee and the Select Committee on Children. Judy will expand her coalitions and advisory council list in addition.

I will let Mary Beth how many 3rd year residents will need to fulfill these competencies between February and June. I will send Judy the 3rd year of the curriculum.

Follow-Up:
As needed

Submitted by:
Christy Berr

Cc: Dr. Mary Beth Bruder

530_800

Agenda
January 4, 1999

Attendants
Judy Blei
Mary Beth Bruder
Christy Berr

1. Evening Seminar
   - February 4th?
   - Topic different this time? (added twist of upcoming legislation)
   - Objectives (2-3)
   - Preparation (handouts, equipment needed?)

2. Resident Visits
   - Observation of a legislative hearing, task force, or leg public hearing , public hearin administratio has press conferences.
   - Meet with a legislator
   - Observation of a Local or State Interagency Collaborating Council or Advisory Council
   - "Legislative Committee Meeting" of the Academy - once a month (when, where, contact?) (in the evening)
   - Other Committee Meetings throughout the session
   - Advocacy Project

3. Best way to contact Judy — 524-1092-fax
   525-9738-Judy.

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APPENDIX M

Scheduling Computer Program:
Meeting Records
DeSai Proposal

Meeting Record

Date: March 29, 1999
In Attendance:
John Mele
Richard
Kara Maslar
Ilene Staff
Christy Berr

Agenda:
1. Computer program for scheduling
2. Connecting with SPSS
3. Using e-mail and the web
4. Time frame and cost

Summary, accomplishments, recommendations:
Using my current forms for scheduling, I reviewed exactly the steps that I take for scheduling the residents. I reviewed with the consultants what I would want the new program to do:

1. After inputting the residents past experiences, the program should be able to schedule each resident for what ever visits that they need in the future in the sequential order of the curriculum. I should be able to pull up a resident's name and know approximately where in the curriculum they will be at any point in time that year. After the dates that we have each resident are manually imputed, the program will produce the block schedule. This schedule will then be e-mailed to the residents that are in that particular block, plus Dr. Zalneraitis, Dr. Laurie O'Neill, Dr. Zavosky, Dr. Peg O'Neil, Dr. Carl Orkin, and all three of the chief residents. As changes occur in the schedule, the updated schedule will be e-mailed out to the particular people I have chosen. I will have an option built in so that I can have easy access to the residents, plus the above Dr.'s e-mail accounts and do not have to leave the program to e-mail.
2. In the event that a resident will not be doing a visit, for example, because they have not identified a family to follow yet, there will be a code for me to enter (or it will default to) to tell the program to skip this visit continuously until I tell it to bring the visit back. If the resident will not be doing a particular visit at all, I can also indicate that so that the program will not keep trying to schedule it. I will be able to say if this happens…then do this. There will be flexibility built into the system. I will be able to override any of the dates or visits that the program schedules. So if I change a date with the chief resident, I will be able to easily fix it on the computerized schedule.
3. Each resident will be thought of individually, not as a group of PL 1's or 2's. This will then accommodate the flexibility needed with adult learning. If a resident goes to a visit that does not fit into the specific curriculum visits, such

as a conference, then there will be a module 10 “Other”. I will then still be able to keep track of all of the visits.

4. The program will have all of the places and directions to those placements so that I can just click on a resident on a particular date (the computer already knows what visit he/she is doing on that date) and then I choose where the visit will take place and the computer will produce an informational sheet (which I now produce in Word) with all of the needed details of the visit. This detailed information (time, place, contact name, special considerations, etc), for each placement will need to be entered only once (while making the program) and then the computer will continually draw on it to produce these sheets. These information sheets can then be e-mailed automatically to the resident if I choose. I would prefer to look each one over before it is e-mailed so that I can make any changes that may be needed (for example, contact name for that particular day may be different).
5. The program will have a space for me to mark when visits have been confirmed with a placement and then produce a sheet letting me know what I still need to confirm. This section of the program will be comparable to my activity schedule now.
6. Once a week has gone by, I can click and make the program produce a report of what happened that week. This report can then be given to Kara to enter into SPSS. This will cut down on her time inputting considerably just because of the way that the data is presented. We may be able to connect SPSS with this program. Richard is looking into it. We would like to have Kara be able to skip this status input if possible, but this part may not be able to happen.
7. If a visit does not occur, I will have a way to let the program know that, and then the program will rearrange that resident’s schedule to accommodate this. With the flexibility in the program, I will be able to override and enter visits at any point so changing the schedule, if needed, will not be a problem.
8. When a new batch of residents enters into the program, their information will be added. The third year residents will not be dropped after graduation, they will just no longer be scheduled.
9. For now, we will have everything go through the e-mail to the residents. This will save enormous amounts of time in travel to drop off the information sheets and directions (including the time that it takes to produce the information sheets and directions.) This will also help the resident so that if they forget the directions at home, they can just print another copy off of their e-mail. I would like to see a space on the web page for this grant. In that section would be the curriculum and directions to placements. This way, the resident can at anytime use the curriculum as a resource, they can print evaluation forms if they need them, and they can print directions if they need them. We could have a direct link in this section to my e-mail so that they can have easy access to communication with me. I asked Kristen when she thought the web would be up and running and if I could add to it. She said as soon as possible, but Mary Beth is still in the process of hiring someone to set it up. She didn’t feel it would be a problem to add this type of information to the web page but confirmed that we needed Mary Beth’s OK first.

10. John will let me know by the end of the week what he and Richard feel the time frame will be and what the cost will be. He sees this project broken into three parts, (1) information collected-requirements, (2) producing the program, and (3) maintenance.

All in all, this program, when produced, will save enormous amounts of time. I estimate that I spend approximately 4-5 hours producing the actual schedule for each block, approximately 15 hours each week producing the informational sheets, and 1 ½ hours each week (not counting driving time) at CCMC dropping information for the residents. Even though this is just an estimate, the program will still save considerable time. Richard said he figures it will only take about ½ hour – 1 hour each week (once I get the hang of the program) to do it all. I will still have to call and confirm visits in addition, which is time consuming, but can not be avoided.

The program will also provide the residents with easy access to their schedule and visits. It will be accessible by other people besides Christy so that if she is out sick or on vacation, everything doesn't rely on her. If we get the schedule on the web, I will also then have access to it from my home or CCMC (if I can get access to a computer over there!).

Added note: John has been working with Scott Westone, here at UConn Health Center to produce an interactive training site on the web. He gave me a demonstration of the program; it was terrific. You can produce presentations, take questions and answer them, etc. I wonder if we might be able to use this type of program for some of the other grants. I don't feel it would meet my need for training in the physician's grant but it certainly is a terrific tool.

Follow-Up:
John will call me by the end of the week.
I will e-mail John the scheduling checklist as an attachment and the estimated hours I work on scheduling.

Submitted by: Christy Berr

CC. Dr. Mary Beth Bruder
Ilene Staff
Kara Maslar
Gerri Hanna

Meeting Record

Date: March 22, 1999
In Attendance:
John Mele
Richard
Christy Berr

Agenda:

1. Computer program
2. Cost
3. Time

Summary, accomplishments, recommendations:
I have spoken to John Mele, from Desai Microage, numerous times in the past. After an overview of what we were looking for in a computer-scheduling program, John decided that he needed to consult with a colleague Richard. Both Richard and John will be working on this program. This morning we had a conference call between the three of us. We reviewed what I needed this program to do: (1) database of residents, (2) schedule of activities (the curriculum), and (3) run the schedule with the capability to be flexible and move things around. They both agree they need to create a program; there is none in existence that would suit our needs.

We will all meet at their office next week to discuss the details of the program. At this point, John feels they will have a better idea of how much time and work will go into this job and will then be able to give me the cost and a time frame. At that point, I will take the information back to Dr. Bruder and discuss it with her. I will need her OK for the project to proceed further. The meetings before to gather information will be of no cost to us.

I informed Richard that (1) this is a grant with limited funds, and (2) it will take time to process the request for payment since it has to go through many channels at UConn Health Center. He said he was aware of this and this was fine.

Follow Up:
John is calling me with an exact time and date for next week this afternoon. It will be Monday, Tuesday, or Wednesday morning or next week.

Submitted by:
Christy Berr

CC. Dr. Mary Beth Bruder
Gerri Hanna
Ilene Staff

Memorandum

To: Mary Beth Bruder

CC: Ilene Staff, Kara Maslar, Gerri Hanna

From: Christy Berr

Date: 01/29/99

Re: Computer Program

I spoke with David O'Sullivan regarding the computer program we would like to have for scheduling the pediatric residents. After hearing a description of the needs of this program, he spent one week trying to see if he could alter existing programs to do what we needed. He does not believe that any existing software can provide us what we need. They do not have the capability to be "flexible" enough. He suggested a custom designed software package. He will not be able to give the project the full attention that it would need and suggested a company that writes software as a full time business. He gave me four recommendations. They are as follows:

1. De Sai Micro Systems in West Hartford on Oakwood Avenue
2. Matka in Simsbury on Hot Meadow Street
3. TCA Agency in Hartford (this company tends to deal well with the state and their restrictions)
4. Source EDP (a company that contracts out to freelance developers)

He gave me some suggestions as we begin to work with any company:

1. Make sure this company does not have any problems doing business with the state, i.e. purchase orders
2. Pay upon delivery so we are not penalized for it taking them longer than they had expected, or if they decide they can not produce it
3. Does there need to be a bidding process? Do we need permission from the UConn Health Center? Do they have a contractor or company we should be using?
4. Make sure the company will come back after delivery to work out any bugs in the system and/or do modifications if it is not working
5. Will they work here or at their own place of business? If they are at their own place of business and billing by the hour, it is easy to be taken advantage of - bill by the job, not the hour

I thanked Mr. O'Sullivan very much for all of his time and assistance. I will draft a thank you letter to send to him.
In regard to suggestion #3, how should we go about finding this out?
Should I begin calling the recommended companies?
What should be our next step?

Memorandum

To: Mary Beth

CC: Ilene Staff

From: Christy

Date: 01/19/99

Re: Scheduling Software

I spoke to David O'Sullivan, the man Nancy suggested we talk to for the computer program. I told him briefly what we would want a computer program to do and asked if he knew of any program out there that did this or if he could create one. He said that he would take what information I gave him, do a little of investigation work and see if he feels he can fit our needs into a program that already exists. He stated that our possibilities *may be* to (1) use an existing software program and have him add to it to make it what we need, (2) have him produce a custom package, and/or (3) he will refer to someone else. He is not sure yet which is the most appropriate. It is possible that he is not qualified to do what we need and/or does not have the time or can not do it in our time frame. I told him we wanted it as soon as possible but would wait if it was our only option. He is getting back to me on Monday of next week to let me know if he thinks it can be worked into an existing program or if we would need to have one customized. This current work will cost us nothing but he will charge if he is going to either contract with us to add to or create a program or if he going to recommend someone (if he is unable to do it himself).

After he calls me back next week with the information, I will set up a meeting with him to discuss what ever the outcome is further. I would like Ilene to be there, as she is the computer pro in this office and yourself. Are there any days/times that are better for you than others?

University of Connecticut Health Center
School of Medicine

January 28, 1999

David O'Sullivan
119 Wellington Drive
Farmington, CT 06032

Dear Mr. O'Sullivan:

On behalf of the Division Director, Dr. Mary Beth Bruder and the pediatric residents, I want to thank you for your assistance and time problem solving our challenge of finding a computer program to suit our scheduling needs. The information you provided about the different programs and their capabilities was extremely valuable. Your recommendations and advice has given me direction in the maze of computers!

Although we are not going to be utilizing your services for this particular job, we will surely look to you in the future.

Thank you again.

Sincerely,

Christy Berr

Christy Berr, M.Ed., MA
Physician's Project Coordinator
Division of Child and Family Studies

n *Equal Opportunity Employer*

3 Farmington Avenue
ngton, Connecticut 06030

DeSai Consulting
Group, Inc.
44-2 Griffin Road
South
Bloomfield, CT
06002-1352

Application Development Proposal

for

Department of Child and Family Services

University of Connecticut Health Center

School of Medicine

April 9, 1999

Submitted by John Mele

DeSai Systems, Inc.
email: jmele@desai.com
(860) 286-9696 x820

Introduction

This proposal, submitted by DeSai Consulting Group, is to develop, test, install and maintain a customized "Pediatric Residency System (***PRAS***)." This proposal covers the Envisioning, Planning, Development, and Knowledge-Transfer Training phases of the project.

DeSai will deliver services described in this proposal under the Terms and Conditions described in Appendix A, DeSai Consulting Master Services Agreement Work Order AW-O1.

Project Overview

A PC-based Scheduling System will be developed, tested and installed for use by the Department of Child & Family Services (DCFS) at the University of Connecticut Health Center (UCHC). This application will reside in the UCHC network environment and will automate the current manual system of scheduling and tracking the Pediatric Residency Rotation Program within DCFS.

Once implemented, ***PRAS*** will maintain an accurate and up-to-date scheduling program to support the three year curriculum undertaken by Pediatric residents enrolled at UCHC. The system will satisfy the needs of the DCFS program director, UCHC pediatric residents and administrators, faculty and other individuals and organizations outside UCHC who support or participate in the program. With a successfully implemented ***PRAS***, the DCFS will achieve:

- Intra and interdepartmental tracking and communication of schedules (director, residents, faculty)
- Reduced program director and staff administrative load
- Improved access for all stakeholders via UCHC Intranet and Internet
- Centralized repository of accurate and important information

DeSai Consulting will work with DCFS by:

- Provide application development services
- Train for application use
- Develop and implementing Version 1.0 of DCFS- PRAS solution

Project Scope

DeSai Consulting recommends an overall ***PRAS*** Solution Development Project consisting of two phases:

- **Phase I,** which consists of the planning and design necessary to build the PRAS Solution
- **Phase II**, which consists of the implementation and development necessary to install ***PRAS***
- Subsequent phases can be considered to extend application functions and features to other scheduling programs within UCHC.

Phase-I – (Planning and Design)

Phase I consists of clearly defining and documenting the following:

- The business problem(s) and how ***PRAS*** will deliver a solution
- The basic requirements for which the ***PRAS*** solution is built
- DCFS strategy for ***PRAS*** Implementation

- The basic design of the ***PRAS*** system
- The products and technologies used to design and implement the solution
- The scope of the solution development project, including:
    - Deliverables
    - Acceptance criteria
    - Constraints
    - Risks
- Project Team roles, responsibilities, and staffing criteria required to implement the solution
- The process used to manage the implementation and installation
- The approximate time line for the implementation phase of the project

Phase-I Deliverables

The main deliverable provided under this phase is a **Planning Service Report.** A draft table of contents is included in Appendix B. The report will:

- Define the scope of the ***PRAS*** Solution Development Project from work process, technical, application, and implementation perspectives.
- Provide a clear understanding of:
    - The Pediatric Resident DCFS environment
    - The PRAS Solution
    - How the project will be delivered successfully to DCFS

A draft table of contents of the Planning Service Report is contained in Appendix B.

Phase-1 Schedule

Based upon our understanding of DCFS requirements, DeSai Consulting believes that the duration of the Phase 1 will be approximately 2 weeks. We will deliver the Project Solution on a mutually agreed-upon schedule after approval of this proposal, *DeSai Consulting Master Consulting Agreement, Work Order AW-01.*

Phase-II (Implementation and Development – Version 1.0)

Phase II consists of implementation and development of Version 1.0 of ***PRAS***. DeSai staff will create an off-site development, testing and production environment. This effort includes the following:

- Information Flow Diagrams
- Outlook Email integration
- Integration of ***PRAS*** with Microsoft Word
- Enterprise Integration (i.e., with Intranet site,)
- Web Page output of scheduling information
- Graphical User Interface design (GUI)
- Database(s) Implementation
- Training for key end users and

- Deployment of a ***PRAS*** Pilot Version
- Release of Version 1.0 application

Phase-II Deliverables

The main deliverable provided under this phase is an operational version of ***PRAS***. This major features will include:

- For DCFS ***PRAS*** users:
  - Will allow access to appropriate information as per Phase-I definitions.
  - Improved e-mail usage by utilizing Intranet, resulting in better information management of all types of documents.
  - Will allow them to easily publish relevant information to internal customers and external service providers.
- For DCFS Management:
  - Centralize document management and information publishing
  - Allow improved intra and inter-departmental communication within UCHC
  - Move quickly towards integrating Internet into business processes for customer growth initiatives

Phase-II Schedule

Based upon our understanding of the DCFS requirements, DeSai Consulting believes that the duration of Phase 2 would be 4 weeks.

Cost Estimates for Phases I and II

Our estimates of resource, time and costs for the entire ***PRAS*** project are summarized in the table below, based on the information collected during phone meeting and a single visit with the Project Director. We will update our estimates with a higher degree of confidence during Phase I.

- Table 1 – Estimated Costs for Phase-I and II

Resource	*Role*	*Estimated Hours*	*Estimated Cost*
Senior Consultant	Project Leader, Functional Specification and Design, Development	40	$ 4,000
Consultant/Developer	Microsoft Developer, SQL, VB, Access, VB Script, Visual Interdev	150	$ 11,250
Programmer/WEB Designer, Tester, Technical Writer	WEB Site Design, Forms, Templates, HTML, Publishing Standards, Documentation	150	$ 12,250
Total Est. Time Costs		**340**	**$ $27,500**

Notes:

- Estimates provided in Table 1 are based upon DeSai Consulting' current understanding of the length of time required in similar types of consulting engagements.
- If the actual time to complete the deliverables defined for the DCFS- PRAS Solution Development Planning Project is less than anticipated, DCFS will be invoiced only for actual effort expended.
- If DeSai Consulting determines the actual effort will be greater than estimated, DeSai Consulting will inform DCFS, and a mutually agreed-upon decision on whether to proceed will be made.

Attachments

The following attachments are include to further define the services DeSai Consulting will provide in this proposal:

- Appendix A: *DeSai Consulting Master Consulting Agreement,* Work Order AW-01
- Appendix B: *Sample Contents of DCFS- PRAS Solution Development Final Plan*
- *Appendix C:* ***PRAS*** Overview

Appendix A
DeSai Consulting Master Service Agreement
Work Order **AW-01**

This Work Order is made pursuant to the DeSai Consulting Master Service Agreement (the "Agreement") effective on _______________ by and between DCFS. ("Company") and DeSai Systems, Inc. ("DeSai") and is incorporated therein by reference.

1. Services.

   a) DeSai Consulting shall perform the services identified below for Company.

   b) Dates provided herein are estimates only.

   c) DeSai Consulting shall deliver the project, DCFS- PRAS Solution Development Solution, as defined in the DeSai Consulting proposal, dated April 9, 1999.

   d) Services provided under this proposal are limited to technical consulting in the area of developing a software application (PRAFS) for DCFS.

2. Rates.

a) The hourly rates shown in the following table shall be applicable to this Work Order and the technical consulting services defined in the proposal, *DCFS- PRAS Solution Development Planning.*

b) Any total fee stated herein is an estimate only.

• DeSai Consulting Rates	
Team Member	*Standard Hourly Rate*
Senior Consultant	$175
Consultant/Developer	$150
Programmer/Analyst	$100
Windows Developer Technical Writer; Testers	$70
Administrative or Clerical	$40

c) DeSai shall invoice Company monthly for services performed and expenses incurred during the previous month.

d) All invoices shall be due upon receipt.

e) DeSai invoices for payment should be directed to Company's representative for payment at the address shown below. (Company to provide).

Contact:
Address:
City: State Zip
Mailstop (if any):
PO #(if any)
Telephone:

3. Commencement Date.

   a) Services under this Work Order will begin at a date to be agreed upon by UCHC and DeSai.

   b) The Expiration Date of this Work Order is June 30, 1999, or such later date as the Work contemplated by this Work Order has been completed.

4. Ownership and License.

   a) Any commercial off-the-shelf product of DeSai or a third party ("Commercial Product") which is provided pursuant to this Work Order shall be licensed to Company according to the terms of the end user license agreement packaged with such product.

   b) All rights in any computer code or materials developed by or for DeSai or Company independently of this Agreement that are provided pursuant to this Work Order ("Pre-Existing Work") shall remain the sole property of the party providing the Pre-Existing Work.

   c) All rights in any computer code or materials (other than a Commercial Product or Pre-Existing Work) developed by DeSai and provided to Company in the course of performance of this Work Order ("Developments") shall be jointly owned by Company and DeSai.

   d) All copyrights in any Development provided to Company in the course of performance of this Work Order that have specific applicability to Company's business such as specific forms, algorithms or calculation methods and that are identified by Company as such during this Work Order (the categorization of which is agreed upon in writing by DeSai) shall be owned by Company.

   e) Each party shall be free to use, reproduce, and modify the Developments for any purpose whatsoever, without any obligation of accounting or payment of royalties, provided that Company agrees to limit its use, reproduction, and modification of Development for its internal business operations.

   f) Each party shall be the sole owner of any modifications that it makes based upon the Development.

   g) DeSai hereby grants Company a non-exclusive, perpetual, fully paid-up license to use, reproduce, and modify Pre-existing Work for its internal business operations.

   h) Company hereby grants DeSai a non-exclusive license to use, reproduce, and modify any Pre-existing Work of Company during the performance of this Work Order.

   i) Company may sub-license the rights granted hereunder to its affiliates (any entity controlling, controlled by or under common control with, Company).

   j) All rights not expressly granted, are reserved.

THEREFORE, the parties have executed this Work Order in duplicate originals.

DeSai SYSTEMS, INC. 199 Oakwood Avenue West Hartford, CT 06119	COMPANY ____________________ ____________________ ____________________
____________________ Signature	____________________ Signature
____________________ Name (Print)	____________________ Name (Print)
____________________	____________________

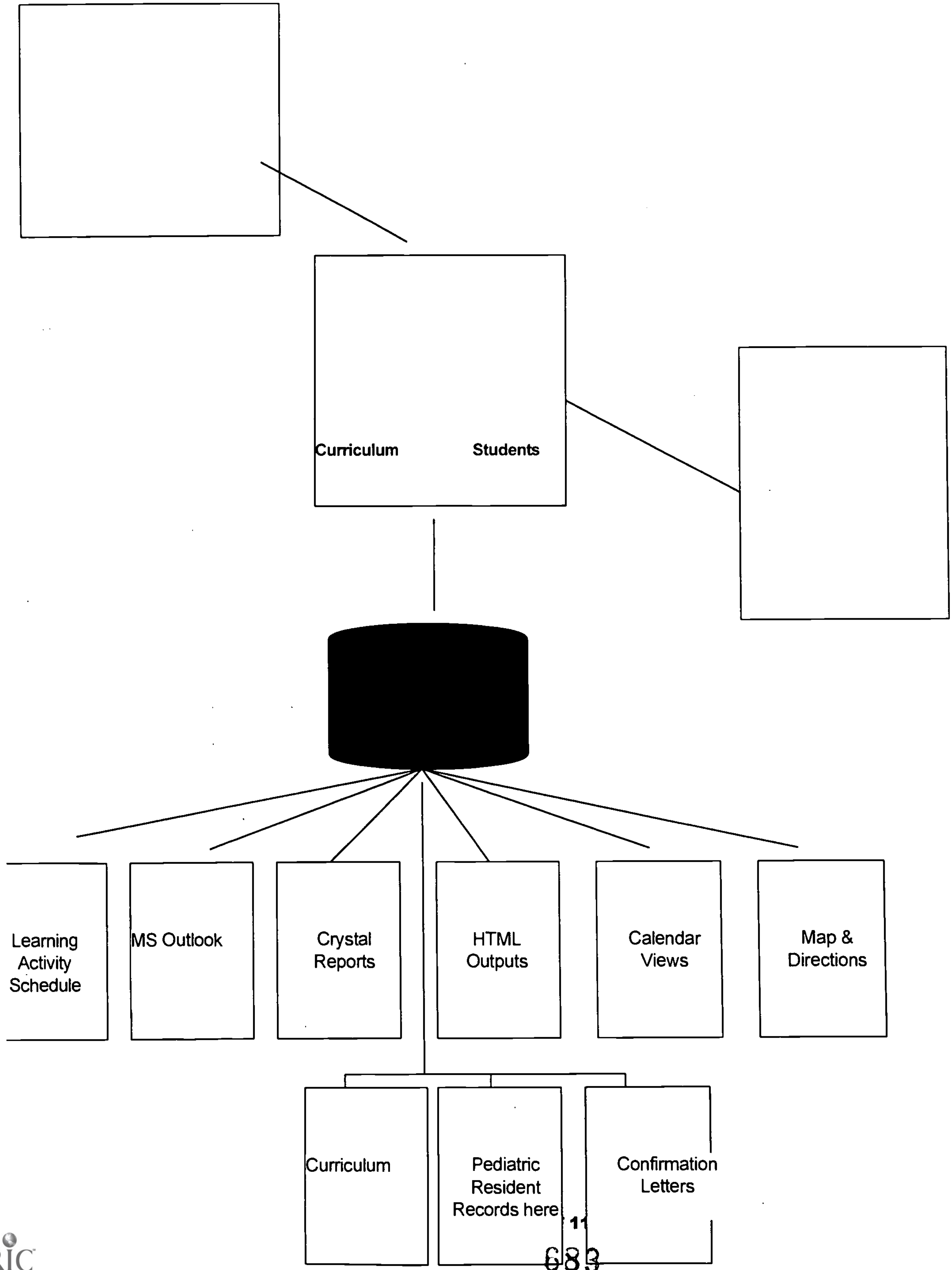
Title	Title
Date	Date

Appendix B

Sample Contents of DCFS- PRAS Solution Development Final Plan

1. Executive Summary
2. Background
   - 2.3 Project Initiation
   - 2.4 Purpose
   - 2.5 Scope of Planning Service Engagement
3. Customer Environment Review
   - 3.1 Organization
   - 3.2 Corporate Standards
   - 3.3 Information Systems Infrastructure
   - 3.4 Related Systems
   - 3.5 Technical Skill Level
   - 3.6 Operational Support
4. Problem Analysis
   - 4.1 Key Objectives and Success Factors
   - 4.2 User Profiles
   - 4.3 Usage Scenarios
   - 4.4 Business Solutions Roadmap
   - 4.5 Product Vision
   - 4.6 Constraints
   - 4.7 Risk Assessment
5. Preliminary System Design
   - 5.1 System Overview
   - 5.2 External System Interfaces
   - 5.3 Functional Module Definition
   - 5.4 Web Site Content and Layout
6. Preliminary System Specifications
   - 6.1 Overview of the Required System
   - 6.2 General Requirements
     - 6.2.1 System Security
     - 6.2.2 System Standards
     - 6.2.3 Internationalization
     - 6.2.4 System Performance
     - 6.2.5 System Capacity
     - 6.2.6 System Availability
     - 6.2.7 Future Expansion
     - 6.2.8 User Interface
     - 6.2.9 Access Control

Exhibit C –***PRAS*** Overview



APPENDIX N

Resident Continuity Clinic Family Chart
Non-Continuity Clinic Families
Guidelines for Working with Families That Speak Spanish
Guidelines for Working with Interpreters
Permission Slip for Continuity Clinic Families

Resident's Continuity Clinic Families
1999/2000

PLI

Resident's Name	Child's Name	Child's Age	Child's Disability
Dwelle, Todd	Dwena	Unknown	unknown
Gard, Robert	Maleehah	7 years	Angelman's Syndrome
Hardarson, Hordur	Brice	9 years	Asbergers Syndrome
Koller, Darwin	Willi	13 years	Down Syndrome
Montgomery, Kathryn	Adrian	4 months	Down Syndrome
Niedzwiecki, Dena	Hector	5 years	Bilateral hearing impairment
Pease, Allison	Izalyn	5 months	Prematurity-develpmentally delayed, failure to thrive, vocal cord paralysis
Rappaport, Jessica	Unknown	3 years	Hearing Impaired-Cochlear Implants
Weeks, Bevin	unknown (2 children-same family)	unknown	Autism
Wong, Faye	Crystal	2 months	Down Syndrome

PLII

Resident's Name	Child's Name	Child's Age	Child's Disability
Alerte, Anton	Miguel (Spanish speaking)	13 years	Mental Retardation, Cerebral Palsy, and Aseptic Necrosis of the right femral head
Carlson, Andrew	Christian	2 years	Muscle Disorder, technology dependant
Dunphy, Laura	Tyler	7 months	Intractable Seizures
Flanagan, Dia	Unknown	16 years	Traumatic Brain Injury
Freysdottir, Drifa	Unknown	2 years	Motor and Speech Delay, Failure to Thrive, Premature Birth
Kinsella, Karalyn	Samantha	11 months	Down Syndrome
Lin, Yu-Fang	unknown	6 months	Multiply Impaired, Neurological Damage, Motor Dysfunction, Vision Problems and Hearing Problems, Preterm
Pluta, Kinga	Carlos	20 years old	muscle disease
Schubert, Charles	Nathan	10 months	Esophageal Atresia
Schwab, Jennifer	Gerrade	1 year	Cerebral Palsy, PVL, seizures
Zervas, Sophia	Prince	11 years old	Traumatic Brain Injury

PLIII

Resident's Name	Child's Name	Child's Age	Child's Disability
Binder, Thomas	Orlando (Spanish speaking)	9 years	Learning disabilities, ADD, on Ritalin
Bjornsson, Sigurdur	Christina	2 years	Williams Syndrome
Christ, Mary	Jalmal and Joshua	Unknown	Profound deafness
Dumont, Thyde	Emanual	6 years	Neurologic Impairment, Visual Spacial Issues
Gannon, Jennifer	Tasha Carolyn and Carlos	14 years 1 year, 3 years	Achondroplasia
Grewal, Sajot	Francheles	1 year	Cerebral Palsy, Seizure Disorder
Gudmundsdottir, Frida	Unknown	10 years 4 years	Unknown
Lamoureux, Brian	Darron	2 years	28 week premie, language delay, motor delay
Nathanson, Allyson	Fernando (Spanish speaking)	3 years	Hearing Deficit, Speech Delay
Nicpon, Christopher	John	10 years	Duchenne Muscular Dystrophy
Rindfleish, Amy	Charlese	8 years	Cerebral Palsy, Mental Retardation, Cortical Blindness

PL III (continued)

Resident's Name	**Child's Name**	**Child's Age**	**Child's Disability**
Thangamuthu, Vasuki	Nathanial	18 months	Down Syndrome, s/p duod. Atresia repair, s/p repair VSD, s/p repair for Hirschsprungs, s/p repair syndactyly
Wagner, Kirsten	Zoey	8 years	Jaffe- Campanoci Syndrome
Yunis, Joseph	Freddy	4 years	Cerebral Palsy, Bilateral Hip Abnormalities

Graduates 1999

Resident's Name	Child's Name	Child's Age	Child's Disability
Capraro, Andrew	Chantel Bacillo	7 years 18 month	Autism Global Delay, Dysmorphic
Fisk, Eileen	Fernando Rafael	11 years old 3 years old	Cerebral Palsy, Mental Retardation Premie/chronic lung disease
Garibaldi, Karen	Wilson	2 months	Down Syndrome Congenital Heart Disease
O'Connar, James	Christian	1 year	Muscle Disorder Technology dependent
Schoel, Suzanne	Unknown	6 months	Stiff Startle Syndrome
Sheiman, Rachel	Reyanaldo (Spanish speaking)		Developmental Delay and Macrocephaly
Spitzler, Susan	Jose	2 years	Cerebral Palsy
Thomas, Christine	Moni (Spanish speaking)	5 years	Degenerative Neurological Disorder with seizures
Wheeler, Lara	unknown	3 years old	Developmentally delayed, Mental Retardation
Whelan, Kirsten	Kentrel	13 months	Herpes Encephalitis

Graduates 1998

Resident's Name	Child's Name	Child's Age	Child's Disability
Boheem, Erica	Anthony	4 years	Pervasive Developmental Delay
Guerrera, Michael	Maribell (Spanish speaking)	3 years	Jarcho-Levin Syndrome
Joshi, Anita	Alex	Unknown	Unknown
Lavalette, Jack	Miguel	10 years	Cerebral Palsy, Mental Retardation, Unclear etiology
Nowacki, Laura	Kelly, Timothy, Daniel and ___	11 years, 7 years, 5 years, 2 years	Congenital disorders
Somanath, Bidarkote	Max	7months	Hypertonia, G-Tube, Bilaterial Grade IV Intraventricular bleeds
Turjoman, John	Jose Janet	1 year 6 years	Cardiac issues GI, Failure to Thrive, on oxygen/ Anuvasis, Seizure Disorder

THE SCHOOL OF MEDICINE
OF THE UNIVERSITY OF CONNECTICUT HEALTH CENTER

Permission to Release Information for Physician's Training

Child and Family Studies
University of Connecticut Health Center
263 Farmington Avenue
Farmington, CT 06030

____

Child's Name Birth Date

The above named child and the child's family are participating in the Physicians Training Project through Connecticut Children's Medical Center and UCONN Health Center. The family has given us authorization to contact the Local Education Agency and/or Birth To Three Program regarding this child, as follows:

The UCONN Health Center is hereby authorized to contact my child's school and or Birth To Three Program, ______________________ and the Board of Education in the city/town of ______________________ to discuss my child's educational and developmental program with appropriate staff, and to visit the school or natural setting to observe my child's educational and developmental program. The UCONN Health Center is also authorized to observe and participate in team meetings regarding my child.

The purpose of this contact is to provide information, observations, and experiences that will assist in training pediatric residents through the Physician's Training Project at Connecticut Children's Medical Center and the UCONN Health Center in Farmington, CT.

______________________________ ____________

Parent/Legal guardian signature Date

______________________________ ____________

Witness Date

Any information shall remain confidential, and shall not be transmitted to anyone else without written consent or other authorization as provided in the Connecticut General Statutes.

This authorization may be revoked by me at any time, except to the extent that action has been taken in reliance thereon. This authorization, unless expressly revoked earlier, expires in one year from the date signed.

THE UNIVERSITY OF CONNECTICUT HEALTH CENTER

Permission to Release Information During Physician's Observations

Child and Family Studies
University of Connecticut Health Center
263 Farmington Avenue
Farmington, CT 06030

School Name Town

The above named school is participating in the Physicians Training Project through Connecticut Children's Medical Center and UCONN Health Center. The UCONN Health Center requests parent/guardian permission to observe ________________ (child's name) in this school setting and inquire about his/her educational program.

The UCONN Health Center is hereby authorized to observe my child in the classroom and discuss my child's educational program with appropriate staff.

The purpose of this contact is to provide information and observations that will assist in training pediatric residents through the Physician's Training Project at Connecticut Children's Medical Center and the UCONN Health Center in Farmington, CT.

Parent/Legal guardian signature Date

Witness Date

Any information shall remain confidential, and shall not be transmitted to anyone else without written consent or other authorization as provided in the Connecticut General Statutes.

This authorization may be revoked by me at any time, except to the extent that action has been taken in reliance thereon. This authorization, unless expressly revoked earlier, expires in one year from the date signed.

Physicians Training Locations

Family Visits

Bozenhard Family
Davenport Family
Drost Family
Gianette Family
Greenier Family
Horn Family
Johnson Family
Joy Family
McNabb Family
McQuaid Family
O'Freil Family
Peck Family
Picklesimer Family
Pullaro Family
Resident Continuity Families
Skeggs Family
Small Family
Steinbrick Family
Sullivan Family
Thompson Family
Udice Family
Zarich Family
Zieper Family

Hezekiah Beardsley
Connecticut Chapter
of the
American Academy
of Pediatrics

invites you to the

1999
ANNUAL CHAPTER MEETING

Friday
April 30,1999

Water's Edge Resort
and Country Club
Westbrook, CT

PROGRAM

12:30-1:45PM *"Improving Preventative Services for Children and Adolescents"* Bright Futures Campaign
Jonathan Klein MD, MPH
University of Rochester, Rochester, NY

1:45-3:15 PM *"CPT and Pediatric Coding Issues"* Peter Rappo, MD, President, MA-AAP, Chair of Council on Pediatric Practice, AAP

3:30-4:15PM *"Pre-Sports Participation Physicals"* Michael Lee, MD, Fairfield, CT Chair, CT- AAP Sports Medicine Committee

4:15-5PM *"The State of Children in Connecticut"* Shelley Geballe, Esq., Co-Director, Connecticut Voices for Children

6PM Cocktail Reception
Awards
Scientific Assembly ← Eileen Fisk, MD presents!

7PM Dinner

8PM Guest Speaker
Stu Silverstein, MD
"Humor in Medicine???
You must be Joking"

CME Credits available

Norwalk Hospital is accredited by the Connecticut State Medical Society to sponsor continuing medical education for physicians. Norwalk Hospital designates this continuing education activity for 4.5 credit hours in Category 1 of the Physicians Recognition award of the American Medical Association (AMA).

Registration Form

Name____________________________

Address__________________________

City_____________________________

State____________________________

Zip______________________________

Telephone________________________

Registration deadline: April 20, 1999

Cost of Registration:

$50 per Member and Guests

No charge for
Residents & Training Fellows

Please make checks payable to CT-AAP

Choice of Dinner Entree:

___ Stuffed Chicken ___ Filet Mignon
___ Filet of Boston Sole

Please return registration to:

Jillian Wood, Exec Director
135 Broad Street
Hartford, CT 06105

Children with Disabilities Rotation

UCHC
Department of Pediatrics
Division of Child and Family Studies

Guidelines for Working with Interpreters

- Get to know the interpreter before meeting with the family. Find out how much s/he knows about:
    - Early intervention
    - Head Start, Day Care, or Special Education Programs
    - The topic/purpose of your meeting
    - Developmental milestones
    - Assessments
- During your interaction address your remarks and questions directly to the family (not the interpreter). Look at and listen to family members as they speak, and observe non-verbal communication.
- Limit your remarks and questions to a few sentences between translations, and avoid giving too much information at once. Avoid long, complex discussions of several topics in a single session.
- Give instructions in a clear, logical sequence. Emphasize key words or points and offer reasons for specific recommendations.
- Avoid technical jargon, colloquialisms, idioms, slang, and abstractions.
- Speak clearly and somewhat more slowly, but not more loudly.
- Be patient and prepared for the additional time that will inevitably be required for careful interpretation.

Source: Lynch, E.W., Hanson, M.J. (Eds.) 1992. Developing cross-cultural competence: a guide for working with young children and their families. Baltimore, MD. Paul Brookes.

Adapted by the Ninos Especiales Outreach Project. UCHC Dept. of Pediatrics, Div. Of Child & Family Studies. Farmington, CT. (1990-1993)

Children With Disabilities Rotation Conference

Name: ______________________________ Date: ______________

This visit was beneficial to me as a physician.	Yes	No
Overall, I was satisfied with the experience and knowledge gained from this visit.	Yes	No

In your own words, please complete this phrase: This experience provided me...

What might you do differently in your practice as a result of this experience?

Did you have any difficulties during this experience? If yes, please describe.

Please list any questions you may have as a result of this visit.

Additional Comments:

Children with Disabilities Rotation

Guidelines
Arranging Home Visits with Families Who Speak Spanish Only

1. Resident calls Lorna Quiros at Child and Family Studies, (860) 679-3974.
    - -discuss various days that would be convenient for both Lorna and the resident
    - -resident provides Lorna with the families name and phone number

2. Lorna calls the family
    - -first try to arrange the visit for the day the resident is scheduled for a Home Visit
    - -if that day does not work for the family, Lorna will discuss the other times
    - -get directions to the home
    - -tell the family that the resident calling to confirm

3. Lorna will beep resident
    - -tell resident time and date of visit and give them directions

4. Resident calls the family
    - -use translator at hospital to call the family to make an initial contact with the family and to confirm the date and time of the visit

5. Resident and Lorna go to home for the visit

6. Resident will ask Lorna to fill out the preceptor evaluation

7. Resident will fill out the reflective observation and the self evaluation and put them in Christy's box at CCMC 4H

HAT IS ECC?

Early Childhood Caries, or Baby Bottle Tooth Decay is a pervasive oral health problem noted throughout all societal strata. While seen mainly in less advantaged populations, it does affect those more affluent as well. A disease of infants, toddlers, and young children, involving the primary dentition, it leads to long term public and oral health consequences of a potentially devastating nature. The financial impact of costly dental remediation is astronomical and is reflected in the costs for such care borne by all of society.

About The Key Note Speaker

Burton L. Edelstein, D.D.S., M.P.H., is a dynamic, articulate, and compelling speaker on the topics of children's health, dental health, and related issues. As Director of the Children's Dental Health Project, he has been crossing the country, addressing these issues at numerous conferences and symposia. He serves as consultant to the Health Care Financing Administration, the American Association of Dental Schools, and the American Academy of Pediatrics. He is also Director of the Oral Health Initiative of the Health Resources and Services Administration, Department of HHS.

A Pediatric Dentist from Connecticut, Dr. Edelstein is a graduate of SUNY-Buffalo School of Dentistry and the Harvard School of Public Health. He served his pediatric dentistry residency at the Children's Hospital, Boston, as a fellow at Harvard. He has also been a Robert Wood Johnson Foundation Health Policy Fellow.

We are fortunate in having one of our own serve as the keynote speaker for this exciting and historic meeting.

Global Issues - A.M. Program

8:00 - 8:30	Registration and Continental Breakfast
8:30 - 8:45	Welcome and Introductions Howard Mark, D.M.D. Chair of Oral Health 2000 Committee
8:45 - 9:30	**"Kids, Cavities and Congress: *Health Policy for Our Youngest Citizens*"** Burton Edelstein, D.D.S., M.P.H.
9:30- 10:15	**"From BBTD to ECC - *"New Understandings of Etiology and Prevalence"*** Norman Tinanoff, D.D.S., M.P.D., Professor and Chair, Pediatric Dentistry, University of Maryland
10:15- 10:30	Break
10:30 - 11:15	**"ECC Prevention: *Expanding Access to Preventive Services in Washington State*"** Peter Domoto, D.D.S., M.P.H., Professor and Chair, Pediatric Dentistry, Univ. of Washington
11:15 - 11:45	**"Vermont BBTD Initiative: *After two years, why the sudden interest?*"** Tommy Ivey, D.M.D., Director, Dental Health Services, Vermont Department of Health
11:45 -12:15	**Panel Discussion of Global Issues** Dr. Edelstein, Dr. Tinanoff, Dr. Domoto, Dr. Ivey
12:15-1:30	**Buffet Luncheon**

Connecticut Issues - P.M. Program

1:30 - 2:00	**"Connecticut Oral Public Health: *Issues and Solutions*"** Stanton Wolfe, D.D.S., M.P.H., State Oral Health Director, Connecticut Department of Public Health
2:00 - 2:30	***"Great Truths About Dentistry & Medicaid in Connecticut"*** David Parella, B.S., M.P.H., Dir., Medical Administration Policy, Department of Social Services
2:30 - 3:00	***"The Role of the Physician in ECC Diagnosis and Referral"*** Laurie McNeill, M.D., Director of Pediatric Residency Program, CT Children's Medical Center
3:00 - 3:30	**"Findings in the Hartford WIC Study: *Where do we go from here?*"** Joanna Douglass, B.D.S., D.D.S., Assistant Professor, Dept.of Pediatric Dentistry, Univ.of Connecticut
3:30 - 4:00	***"Cultural/Access Issues in the Hispanic Community"*** Grace Damio, M.S., CD/N, Director of Maternal Child Health and Nutritional Services, Hispanic Health Council
4:00 - 4:45	**Panel Discussion of Connecticut Issues** Dr. Wolfe, Dr. Douglass, Mr. Parella, Ms. Damio and Ms. Katherine McCormack, R.N., M.P.H., Director of Health, Hartford Health Department
4:45 - 5:00	***"Planning for Initiative Continuance"***
5:00	Adjournment

Participants eligible for eight hours CE credit

PLEASE COMPLETE THE FORM BELOW AND RETURN BY APRIL 14, 1999. If Hotel Reservations are required, please contact the Marriott directly before April 7, 1999, at 860-678-1000, Registration is limited so a timely response is important. The only fee is for the luncheon. Registration/Luncheon - $29.00. Please remit to: ECC Symposium, Connecticut State Dental Association, 62 Russ Street, Hartford, CT 06106 Attention: Denise Tyrrell. Phone 860-278-5550.

Name:________________
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CSDA
62 Russ Street
Hartford, CT 06106

www.ctdental.org

Connecticut State Dental Association
Oral Health 2000 Committee
&
Connecticut Department of Public Health
invite you to attend the

First Connecticut Symposium on Early Childhood Caries

The challenges of a serious public health problem affecting the developing dentition of infants, toddlers & children in Connecticut.

Wednesday, April 28, 1999
8:00 a.m. - 5:00 p.m.
Farmington Marriott Conference Center
Farmington, Connecticut
Exit 37, I-84 E or W, Farm Spring Road

Open to all concerned with any aspect of this disease: children's hospitals; maternal/infant outreach programs; medical & dental professionals; community & hospital clinics; insurance companies; school-based professionals; and parent groups

This conference is made possible through the generous support of Anthem Blue Cross and Blue Shield of Connecticut; the Connecticut State Dental Foundation; the Dental Practice Association of Connecticut; the Connecticut State Medical Society, the Connecticut Chapter of the American Academy of Pediatrics, the McManus Fund of the Hartford Dental Society; Oxford Health; the Connecticut Section of the Pierre Fauchard Academy; Pfizer Inc.; and others, including the Hartford Health Department; the Hispanic Health Council; and the Urban League of Greater Hartford.

APPENDIX O

Connecticut Chapter American Academy of Pediatrics Annual Meeting
Conference Feedback Form
Sample of Additional Information Distributed to Residents

702

Fact Sheet

Connecticut Disability Determination Services

Providing Evidence for Children's Supplemental Security Income Disability Claims

Supplemental Security Income (SSI) is a needs-based program administered by the Social Security Administration (SSA). SSI disability payments are made to individuals who meet the medical and non-medical requirements (i.e., income and resources) of the law. SSA determines whether children under the age of 18 are disabled by considering not only their medical conditions but also the effect those conditions have on their ability to perform age appropriate activities.

In Connecticut the Disability Determination Services (DDS) is responsible for the medical evaluation of claims for the Federal disability program at both the initial and the reconsideration levels of administrative review.

In addition to reports from medical sources, the DDS requests records from schools and agencies, not only for information regarding psychometric testing and medical evaluation, but also regarding the impact of a child's condition on his or her ability to function in the school/agency setting.

CHILDHOOD LEGISLATION

On August 22, 1996, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 was enacted. This legislation changed the definition of disability for children under the SSI program.

NEW DEFINITION

The new definition of disability for children eliminates the comparable severity standard and provides instead for the following:

- **A child must have a physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations;**
- **The medically proven physical or mental condition or conditions must last or be expected to last at least 12 continuous months or be expected to result in death;**
- **The child may not be considered disabled if he or she is working at a job that is considered to be substantial work.**

The new law also directs SSA to eliminate references to maladaptive behavior in the domain of personal function in the Listings of Impairments for children and to discontinue the use of an individualized functional assessment in evaluating a child's disability.

EFFECT OF NEW LAW ON SOME CHILDREN CURRENTLY ELIGIBLE

Because of the new legislation, we may no longer consider some children disabled. The law requires us to review the cases of certain children who are now eligible for SSI to determine if they are disabled under the new definition of disability for children.

CONTINUING DISABILIY REVIEWS

Continuing Disability Reviews (CDRs) must be conducted at least every three years for recipients under age 18 whose conditions are likely to improve.

CDRs must be initiated not later than 12 months after birth for babies whose disability is based on their low birth weight.

SSA also may conduct CDRs for recipients under age 18 whose conditions are not likely to improve.

REDETERMINATION OF DISABILITY AT AGE 18

Any individual who was eligible as a child in the month before the month he or she attained age 18 must have his or her eligibility redetermined. The redetermination will be conducted during the one year period beginning on the individual's 18th birthday. We will use the same rules as for adults filing new claims.

INFORMATION NEEDED TO EVALUATE CHILDREN'S DISABILITY CLAIMS

Although the new law eliminated the Individualized Functional Assessment (IFA), we often must evaluate a child's functioning in order to decide:

- **Is the impairment(s) severe?**
- **Does the impairment(s) meet or medically equal a listing? (Note: We have a Listing of Impairments for children, which includes very severe criteria that will qualify the child medically for disability benefits.)**
- **Does the impairment(s) functionally equal a listing?**

DETERMINING FUNCTIONAL EQUIVALENCE—FOUR METHODS

I. Limitations of specific functions (Example – loss of hearing or vision),
II. Limitations resulting from chronic illnesses characterized by frequent illnesses or attacks, or by exacerbations and remissions (Example – sickle cell, major motor seizures, schizophrenia, paranoid and other psychotic disorders, repeated manifestations of HIV infection),
III. Limitations resulting from nature of treatment required or effects of medication, and
IV. Broad functional limitations. There are six broad areas of functioning that may be addressed in determining functional equivalence:

1. Cognition/communication, which applies from birth to age 18 – we look at:
    a. The child's ability or inability to learn, understand, and solve problems through intuition, perception, verbal and nonverbal reasoning, and the application of acquired knowledge;
    b. Ability to retain and recall information, images, events, and procedures during the process of thinking;
    c. Ability or inability to produce language in order to communicate, e.g., to respond, as in following directions or answering questions, to request, as in meeting needs or seeking information, to comment, as in expressing feelings and ideas or describing events;
    d. Whether the child's speech is intelligible; and
    e. Whether the child's hearing is adequate for conversation.

2. Motor, which now applies from birth to age 18 – We have extended the use of motor area of functioning to children up to age 18 to make it easier to evaluate older children with physical limitations.

3. Social, which applies from birth to age 18 – It is not true that SSA will no longer evaluate children with maladaptive behaviors; however, the new legislation did eliminate consideration of maladaptive behaviors in the personal domain in the Childhood Mental Disorder listings. Instead, we will consider them in whichever of the six areas of functioning they affect, which will often be in the area of social functioning. Social functioning refers to a child's capacity to establish relationships with parents, other adults, and peers and to interact appropriately, as well as the ability to get along with others, such as family members, neighborhood friends, classmates, and teachers. Impaired social functioning may be demonstrated in other ways, such as inappropriate externalized actions (e.g., running away or physical aggression) or internalized actions (e.g., social isolation, avoidance of interpersonal relationships, or mutism).

4. Responsiveness to stimuli, which applies only from birth to age 1;

5. Personal, which applies from age 3 to age 18 – The area of personal functioning pertains only to self-care; that is, personal needs, health, and safety (e.g., eating, toileting, bathing, dressing, maintaining personal hygiene, proper nutrition, sleep, and health habits, as well as adhering to medication or therapy regimens, and following safety precautions).

6. Concentration, persistence, or pace, which also applies from age 3 to age 18.

OTHER FACTORS:

- Circumstances of chronic illness
- Effects of medication
- Effects of structured or highly supportive settings
- Adaptations, such as assistive devices, appliances, or technology
- Multidisciplinary therapy
- School attendance
- Treatment and intervention

SCHOOL ATTENDANCE

In addition to evaluating how the child is actually functioning in the school setting (academically, socially, and behaviorally), we will consider the child's attendance and class placement in determining his or her ability to function. Since most children, including children with physical or mental impairments, attend school, special significance will not be placed on the fact that a child is able to attend school. On the other hand, we will consider inability to attend school on a regular basis because of medical determinable impairment(s) to be a significant indicator of the child's limited ability to function.

Likewise, because the kinds and availability of special education and the rules for placement in special education vary widely, we will not place special significance merely on the fact that a child is or is not placed in a special classroom setting. We will consider the child's special placement or lack of placement in the context of all the evidence concerning the child's impairment(s).

When a child is given a special education placement, we need to know why the placement has been made; the physical, academic, and/or behavioral needs of the child that prompted the placement; the assessment data (both formal testing and observations) that supported the placement; and how the child is functioning in the special placement compared to the functioning of unimpaired children in regular classrooms. In addition, we will be attempting to obtain school records, especially the PPT/IEP and multidisciplinary team reports.

DOCUMENTATION OF SCHOOL ATTENDANCE INCLUDES:

- Pattern and frequency of attendance and absences
- Cause of prolonged absences, if known (i.e., whether because of the impairment(s) or for other reasons)
- Degree to which the child is able to function in the classroom and other school settings
- Degree to which the child receives special help or accommodation to function at school, including whether the child is in special education settings for all or part of the day

OBTAINING EVIDENCE OF DISABILITY IN CHILDREN'S CLAIMS

"Evidence" is any information that relates to the child's disability claim. Evidence covering at least the 12-month period prior to the date of application is usually needed to establish a record of the child's functioning over time.

MEDICAL EVIDENCE

Medical Evidence includes:

- Reports of objective medical findings and observations based upon examination and laboratory testing (height and weight are very important).
- Results of psychological testing performed by licensed or certified sources, and reported in terms of percentiles, percentages, standard deviations, or chronology (months of delay).
- Other evidence from medical sources, e.g., medical history, opinions, and statements about treatment.
- Statements by the child or other person about the child's impairment(s), related symptoms, and any functional restrictions (or activity of daily living descriptions) due to the impairment(s).

- Copies/summaries of medical records from hospitals, clinics, other medical institutions or health care facilities.
- Reports of an interdisciplinary team(s) that contain the evaluation and signature of an acceptable medical source.

OTHER EVIDENCE

Non-medical evidence helps us to understand the child's ability to function and to establish a record of a child's functioning over time. Evidence from these sources includes, but is not limited to the following:

- Information from public and private social welfare agencies and social workers.
- Statements made by the child, parent, guardian, care giver, or others concerning the child's impairment(s) and the functional effects of the impairment(s) on the child's ability to grow, develop, or mature.
- Other relevant statements, such as ones made by the child, or others who know the child, to Social Security representatives during the interviews, on applications, in letters, etc.
- Statements from nurse practitioners, physician assistants, naturopaths, and chiropractors.
- Information from physical, occupational, or speech and language therapists.
- Information from educational agencies and personnel, (e.g., school teachers, school psychologists who are licensed or certified, school counselors, preschools, early intervention teams, developmental centers, and daycare centers).

SOME MISCONCEPTIONS

Occasionally we learn that there are some misconceptions regarding Social Security disability determinations for adults and children. We have no quotas to either allow or deny disability claims. Our goal is to make the *correct decision* and in a *timely manner* since many individuals are faced with hardship at the time the application is filed. The omission of pertinent information, medical or non-medical, may make a difference in the allowance, as well as the denial of the disability claim.

We DO realize that many of our sources of medical and non-medical evidence are faced with their own workloads and priorities. We make every effort to facilitate this disability determination process and are open to suggestions in order to improve our working relationships.

Jsg-8/97

ANSWERS FOR DOCTORS AND OTHER HEALTH PROFESSIONALS

INTRODUCTION

Doctors and other health professionals play a major role in ensuring that their patients are aware of the provisions of the Social Security disability programs. This booklet answers the questions most frequently asked by doctors and other health professionals about who is eligible, how disability is determined under Social Security law, and how work affects benefits.

1. What are Social Security's Disability Programs?

The Social Security Administration (SSA) manages two programs that pay monthly disability benefits or payments to people under age 65 who cannot work for at least a year because of severe disability: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Medical requirements are the same for both programs.

SSDI benefits are paid to people who have worked long enough and recently enough under the program and to certain family members (e.g., disabled widows(ers) and children). Those who have been receiving benefits for at least 24 months also qualify for Medicare coverage. SSI disability payments are made to adults and children with limited income and resources. No prior work is needed. SSI recipients generally qualify for Medicaid, a State-run health insurance program.

2. Who gets disability benefits?

Social Security disability benefits can be paid to:

- Disabled workers under 65 and their families;
- Individuals who become disabled before 22, if a parent (or in certain cases, a grandparent) who is covered under Social Security retires, becomes disabled, or dies;
- Disabled widows or widowers, age 50 or over, if the deceased spouse worked long enough under Social Security. This also applies to certain disabled surviving divorced spouses over 50;
- Blind workers.

3. What is SSA's definition of disability?

For adults, the Social Security law defines disability as the "inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

For SSI purposes, a child is considered to be disabled under Social Security law if the child has a physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations, and which meets the same duration requirements as for an adult.

4. Why is the definition of disability so strict?

The disability programs are designed to provide long-term protection to individuals who are so disabled that they are unable to do any kind of work in the national economy (or, for children, unable to engage in age-appropriate activities). This is the most difficult type of disability to protect against, and most people and their employers cannot afford to protect against this risk through other means. Short-term disability protection can be provided through other means; e.g., workers' compensation, insurance, family, savings and investments.

Thus, the disability program is meant to provide benefits only for those with the most serious impairments. In that respect, it may be considered very "strict".

5. Who can receive SSI?

Supplemental Security Income disability payments can be made to:

- Disabled persons under 65 who have very limited income and resources;
- Disabled children under age 18;
- Blind adults or children.

6. Who determines whether a person is disabled?

Generally, when a person first applies, a determination whether a claimant is disabled as defined in the law is made for SSA by a team, composed of a physician/psychologist and a disability examiner, working in the Disability Determination Services (DDS) of the State in which the claimant lives. Typically, the physician/psychologist in the DDS maintains a private practice in addition to serving as a member of the team responsible for making the disability determination.

7. Why are patients, who in my opinion, have severe disabilities denied disability benefits by Social Security?

The disability team in the DDS must evaluate all of the elements involved in a disability determination, some of which may not be apparent to a treating physician/psychologist. These would include, when appropriate, age, vocational and educational factors that may contribute to the patient's ability to work.

8. Is it likely that a person considered "disabled" under another program will be found disabled by Social Security?

Not necessarily. The rules in the Social Security law for determining disability differ from those in other Government and private programs. A person eligible for disability payments under one program may not be eligible under Social Security. However, a decision made by another agency and medical reports it obtained will be considered in determining whether a person is disabled for Social Security purposes.

9. Does the DDS team also examine the applicant?

No. It relies entirely on the evidence in the claims folder reported by you and others who have examined or treated the claimant. The DDS examiner of physician/psychologist may contact you to clarify information you submitted, or for addition information.

10. Do all State DDSs use the same medical criteria?

Yes. There is one set of medical criteria used by every DDS. This ensures uniform and consistent adjudication of a claim no matter where the claimant lives.

11. How are Social Security's disability evaluation criteria developed and why does it take so long to update or revise them?

These criteria are developed by Social Security medical and psychological consultants and other program and medical experts. Any change in the medical evaluation criteria for Social Security disability must reflect the latest approved, established medical practices and procedures. This necessarily requires careful and complete consideration of proposed revisions, a process that involves public review and comment.

12. How do I get a copy of the medical evaluation criteria?

The medical evaluation criteria (commonly referred to as the "Listing of Impairments" or the "Listings") are contained in a handbook entitled, *Disability Evaluation Under Social Security,* SSA Pub. No. 64-039. If you would like a copy, call or write the DDS.

13. How is the Listing of Impairments used in deciding cases?

In general, the Listing of Impairments is used as the standard by which the severity of the impairment is evaluated. If a claimant has an impairment or combination of impairments that meet or equal those described in the Listings – and is not working – he or she generally would be considered disabled. If the claimant is doing substantial gainful work, he or she ordinarily would not be considered disabled under the law, despite the severity of the impairment.

Most findings of disability can be made based only on medical considerations. But, if an adult's claim cannot be decided on medical factors alone, then the person's age, education and work experience are considered.

14. What type of information should be included in the medical report for a patient?

Your report should include the history, symptoms, signs and laboratory findings – as much objective data from the patient's chart as possible. You also should include a statement about what activities the patient can still do despite his/her impairment.

15. Who pays for the report?

Social Security can pay a reasonable amount for reports of existing medical evidence it requests from physicians/psychologists, hospitals and other non-Federal providers of medical services. Contact your DDS for its payment information.

16. Is the initial report from the treating physician/psychologist all the medical information that the DDS team needs to decide a case?

In many cases, yes. Frequently, reports from other treatment sources, such as hospitals and clinics, also are used. If the DDS requires certain clinical or laboratory data that was not reported, the DDS may call or write you to find out if you have the needed information in your records.

17. Suppose I do not have the information requested?

Then the DDS may ask if you wish to provide the information by performing tests or an examination for a fee paid by the DDS; or the DDS may send the claimant to an independent medical source for an examination and the required information – if, for instance, you prefer not to do the examination or do not have the equipment to provide the specific data needed. These are called "consultative examinations (CEs)."

18. Who are these "independent medical sources"?

Generally, they are physicians and psychologists in private practice in all specialties. If you are interested in performing CEs, contact the DDS in the State where you practice.

19. How are the fees for consultative examinations set?

Each State determines the rate of payment to be used for purchasing medical or other services necessary to make determinations of disability ,and fees vary form State to State. Federal regulations require that the rates may not exceed the highest rate paid by Federal or other public agencies in the State for the same or similar type services.

20. It takes a lot of time to write up medical reports on my consultative examinations. Can I phone them in?

Yes. Many State agencies (generally referred to as the "Disability Determination Services") employ a teledictation service that enables the consultative physician/psychologist to do just that. The service can be used at any time, including nights and weekends. You receive a typed transcript of your telephoned report to review, sign, and return to the State agency.

21. If I perform consultative examinations, are there any legal considerations of which I should be aware?

Yes. When the DDS contracts with you to do consultative examinations (CEs), you are an independent contractor, and are responsible for conducting the examination in a proper manner, just as you do with your own patients. The DDS does not offer you protection in this situation. We do point out, however, that because you will be conducting an examination only, and performing only those tests that the DDS authorizes, not prescribing treatment, there is little chance of any legal action being filed against you. (Additionally, the DDSs do not order tests that involve significant risk to the patient.) The claimant is advised beforehand that the consultative physician/psychologist does not make the disability determination and that the "CE" evidence is evaluated along with all other evidence in the claim.

22. Can a person appeal a medical determination he or she is not disabled?

Yes. There are several levels of appeal. They are explained in a fact sheet, "The Appeals Process," which is available at any Social Security office.

23. Do benefits stop when a disabled worker who has not recovered goes back to work?

Generally, not right away. A continuing disability review (CDR) is scheduled periodically to determine if there has been any medical improvement sufficient to permit the person to work again. The evidence on which a determination is based included evidence from the treating source, including a statement as to the person's work capabilities. Additional medical/psychological examinations or tests may be required.

A person who attempts to work may continue to receive up to 4 years of support and services involving cash payments and/or health care coverage. The work incentive provisions differ between SSDI and SSI, although some are the same. They include:

- **Nine months of trial work, called a "trial work period" (TWP)** (not necessarily consecutive) during which a person may continue to receive benefits regardless of amount of earnings;
- **A 36-month extended period of eligibility (EPE)** following the end of the 9-month TWP during which benefits may be paid for any month earnings fall below the SGA level (up to $500);
- **Continuation of SSI Eligibility** at least 39 months after the trial work period;
- **Deduction of impairment-related work expenses** in deciding if earnings constitute SGA. (These include wheelchairs and seeing-eye dogs.);
- **Continuation of monthly payments and Medicare or Medicaid** for a person whose impairment has show medical improvement related to the ability to work, if the person is participating in an approved vocational rehabilitation program which is expected to result in allowing the individual to work and become self-supporting.

Additional information about these and other work incentive provisions is contained in the pamphlet, "Working While Disabled: How Social Security Can Help"; and in SSA Publication No. 64-030, *A Summary Guide to Social Security and Supplemental Security Income Work Incentives for the Disabled and Blind*, which are available at any Social Security office.

24. What are "continuing disability reviews" (CDRs)?

The Social Security law requires that all disability cases be reviewed periodically to make sure that individuals are still disabled. The frequency of reviews depends on the nature and severity of the impairment, the likelihood of improvement and other factors. Reviews may range from 6 months for cases in which medical improvement is expected, up to 7 years where medical improvement is not expected.

A person's disability benefits generally will continue unless there is strong evidence of both medical improvement and ability to work There are some exceptions that apply in relatively few instances.

During a review, you may be asked to provide current medical evidence. If an additional examination or test is needed, the DDS team may request you to conduct it; or the individual may be sent to an independent medical source.

A person who gets a notice that he or she is no longer disabled under the definition in the law, may appeal the determination; he/she has special rights not available to those denied upon initial application for disability benefits. The individual may meet face-to-face with the decision maker during the first level of appeal (reconsideration). Benefits may be continued through the first two levels of appeal if this is requested within 10 days after a determination notice is received.

25. How does Social Security identify cases in which a disabled person's condition improves?

Because disabled people are required to inform us if their conditions improve or if they return to work, we may learn of the improvement through self-reporting, or the improvement may be determined as a result of a review of such person's cases.

26. What happens if the individual becomes disabled again?

If a worker becomes disabled again within 5 years after a previous period of disability, he or she will not have to serve a new 5-month waiting period before disability benefits may resume. In addition, if the person was previously entitled to Medicare, that protection will resume immediately. (This provision also applies to disabled widows and widowers, and adults disabled before age 22 whose benefits start again within 7 years.)

27. Can a person receive disability checks from both Social Security and another government agency?

Yes. However, Social Security benefits to a disabled worker and family may be affected if the worker is also eligible for Worker's Compensation (including black lung) or for disability benefits from certain Federal, State, or local government programs.

Total combined payments to the worker and family from Social Security and any of these other programs generally cannot exceed 80 percent of the worker's average current earnings before disability began. The monthly Social Security benefit is reduced when necessary to keep within this limitation. All of the worker's earnings covered by Social Security, including amounts above the maximum taxable by Social Security, may be considered when figuring average earnings.

28. I understand that there are special provisions for blind persons. What are they?

A person who, in the better eye, with the use of corrective lenses, has either a visual acuity f 20/2000or less or a visual field restricted to 20 degrees or less, is eligible for disability benefits if he or she has worked long enough under Social Security. A blind person who is eligible for SSI needs no Social Security work credits.

A blind person is eligible under Social Security for a disability "freeze" even though working. This means that future benefit amounts, which are figured on average earnings, will not be reduced because of low earnings or no earnings in some years because of blindness.

Even if a blind person is now employed or self-employed, he or she may benefit from one of several special provisions for blind people who work. For additional information, see the SSA Fact Sheet, "Benefits for Disabled Social Security Beneficiaries/Recipients who Work" or contact any Social Security office.

29. How can I get more information for my patients?

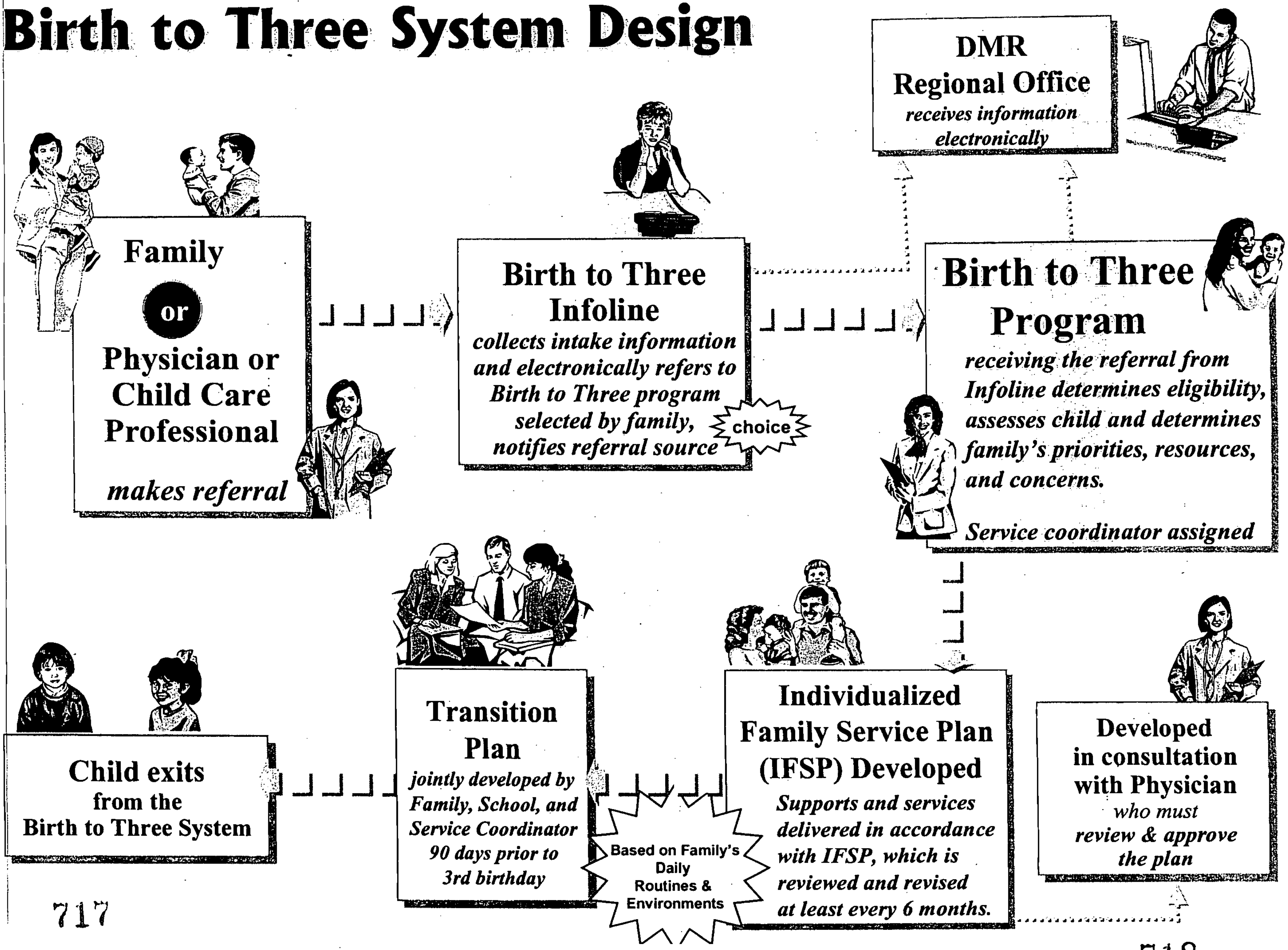
You may contact any Social Security office for more information on any of the facts reported in this booklet. The toll-free number is 1-800-772-1213.

30. How can I learn more about participating in the disability program?

You may contact the Professional Relations Branch at the Social Security Administration's Headquarters. The address is:

Social Security Administration
Office of Disability
Division of Disability Process Policy
Professional Relations Branch
Room 3-A-10 Operations Building
6401 Security Boulevard
Baltimore, Maryland 21235

Birth to Three System Design



Family

or

Physician or Child Care Professional

makes referral

Birth to Three Infoline

collects intake information and electronically refers to Birth to Three program selected by family, notifies referral source

choice

DMR Regional Office

receives information electronically

Birth to Three Program

receiving the referral from Infoline determines eligibility, assesses child and determines family's priorities, resources, and concerns.

Service coordinator assigned

Individualized Family Service Plan (IFSP) Developed

Supports and services delivered in accordance with IFSP, which is reviewed and revised at least every 6 months.

Developed in consultation with Physician

who must review & approve the plan

Based on Family's Daily Routines & Environments

Transition Plan

jointly developed by Family, School, and Service Coordinator 90 days prior to 3rd birthday

Child exits from the Birth to Three System

APPENDIX P

Resident's Comments & Solutions from 3x5 Cards

memo

What are three things you learned?

- 1) Schools are very integrated and many children accept people with handicaps because they are exposed to it every day, 2) Birth to three providers are a great resource to find out about patient's home environment.

- 1) Learned about PPT/IFSP and the effects we may have, 2) Better appreciation for families and how disabilities may effect them, 3) Better understanding about the rights of students with disabilities and the resources schools have.

- 1) How complicated coordinating services are, 2) How expensive and complex it is to set up and lug wheelchair.

- 1) Support services/ referral services available, 2) Functions of the Medical Home, 3) Understanding for the families of children with special needs.

- 1) About Birth to 3, 2) Special Ed., 3) What a PPT is.

- 1) IEP's, 2) Management of deaf children, 3) Advocacy/team management

- 1) What a PPT was and details regarding IFSP, IEPs, 2) What Birth to Three does and what happens between 0 – 3 to grade school (special ed) in the schools, 3) Due Process and parents rights with regards to special ed.

- 1) How Birth to 3 functions (how it really doesn't work the way it's supposed to), 2) Good perspective of how medical home and foster care works)

- 1) All that needs to be done to get a PPT is to ask for one, 2) How much a motored wheelchair costs, 3) How to fill out evaluations in 2 minutes or less.

- 1) How to do PPTs, and the individualized plans for special needs children, 2) Current laws protecting children with special needs, 3) Experienced auxiliary services for disabled.

- 1) Audiology testing, 2) What a physical therapist does, 3) how DCF runs/protocol followed by referral.

- 1) How to get a child involved with Birth to 3, 2) How children with disabilities get services integrated into their school day, 3) Struggles families have had trying to get services for their children.

- 1) Schools responsibilities in regards to children with disabilities, 2) The difficulties of a medical home, 3) The workings of birth to three.

- 1) Differences between IFSP and IEP, 2) Funding sources for children with disabilities, 3) Concept of medical home.

- 1) PPT, 2) Audiology/Hearing screens, 3) Review of Legislator.

- 1) Learned what a PPT is, 2) Learned legislation covering disabled children, 3) Audiology.

- 1) What happens in parent/teacher/special ed school meetings. Re: disabled child needs, 2) How OT/PT/Speech therapists work with disabled children, 3) How the legislative process works, re: disabled children.

- 1) How to advocate for your patients in sight into the laws and legislation process, 2) Contacting with family's of children with disabilities and what problems they run into with doctors and the "system" like insurance, etc., 3) Insight into the role of other professionals and how to improve how we all can work together.

- 1) Learned about resources available, 2) Learning how to "talk the talk", 3) Through this experience, I now feel much better about calling schools and trying to advocate for my patients.

Name one item you would change:

1) I would like to do more activities along with another resident

2) Have > 2 residents for didactics

3) More time with disabled child advocates/often parents (themselves) of a disabled child who can best share their experiences.

4) Change: Combine topics so we don't have so much redundancy.

5) Changes: Doesn't need to be a 3-year program – redundancy.

6) Evaluation forms are too long.

7) Kill the paperwork.

8) I would change…less didactic time.

9) Didactics too time consuming with too much extraneous info. i.e. teach key practical points about leading a team NOT the theoretical aspects (theories).

10) Didactics

11) Evaluations, evaluations, evaluations.

12) What we need is a summary sheet of early intervention because I feel trying to piece it all together from the large binder is kind of hard.

13) To change: All the paperwork and questionnaires – way too much.

14) What I'd change: All the paperwork.

15) What to change: paperwork, more notice for away visits.

16) Some of the activities are repetitive, 1-2 school visits more appropriate.

17) Less lecture time.

18) People in program really treat us like kids and very pushy on what they wanted us to learn/believe.

Name one item you would change: (Each comment on the attached page will be referred to by number)

1) There has been a big change this year getting more than one resident at a time to the didactics (sometimes as many as 4or 5!). Thanks, Suzanne for collaborating with Christy on this. We will continue to do this as long as residents can be freed in groups from the PCC and other sites. At times we have also been able to send 2-3 residents on outside activities together. We will strive to continue with this to the extent possible.

2) See previous comment.

3) We really strive to bring parents of disabled children into all the didactics so that they can share their experiences. If this isn't happening then we need to remedy it from our side.

4) We have done it! We combined modules and visits so that we now have 7 modules instead of nine, and a number of visits have been deleted or combined with others.

5) Well...we aren't going to change from a 3 year program just yet. Hopefully you will see that some of the redundancy has disappeared; however, there is still *some* present in the curriculum simply because repetition isn't a bad way to learn—we can all write scripts for Amoxicillin in our sleep, but Amantadine dosing isn't at the forefront of many resident's (or attending's) knowledge base!

6), 7), 11), 13), 14), 15) We hear you! Much of the paperwork is changing...you will be especially pleased with the pre and post tests. Some of the other evaluations are changing and the forms will be shorter; however, we still need to gather information for the Federal Government who is financing the grant, so there is a minimum amount of information gathering that is needed to be in compliance—bear with us!

8), 9), 10), 16), 17) See#4 above.

12) An early intervention summary sheet is a nice idea. Maybe we can work on it once the curriculum is finished. Any volunteers?

18) Whoever wrote this has had some negative experiences. It would be useful if that person would discuss them with myself or Christy or someone else with whom they are comfortable. With specifics we may be able to do something to ensure that s/he would have a better experience in the future.

APPENDIX Q

Resident Schedule
Sample Information Page

CHILDREN WITH DISABILITIES ROTATION SCHEDULE

Block Number: 12
Dates: April 26 – May 21, 1999

April

M	T	W	Th	F
(AM) Whelan:IAIC Freysdottir: SPED Zervas: SPED Nicpon: AO-Audio Glasser: EIHV	(AM) 27	(AM) 28 Thangamu: TM	(AM) 29 Zervas: SC-Genetics	(AM) 30 Capraro: Vocational
(PM)	(PM)	(PM) Rindfleisch: AO O'Connor: ML Zervas: SC-Cranialfacial	(PM)	(PM) Bjornsson, Fisk & Sheiman: AAP Conference
(AM) May 3 Glasser: SPED-PV Freysdot: SPED-PV Gannon: Whelan: IAIC-DCF	(AM) 4	(AM) 5 Thangamu: TM	(AM) 6	(AM) 7 Nicpon: SPED-PV-CC Fisk: OLH??
(PM) Bjornsson: OLH at the capitol	(PM) Zervas: NICU Follow-Up Fisk: HIGH HOPES	(PM) O'Connor: ADV Project	(PM)	(PM)
(AM) 10 Thangamu: TPF	(AM) 11	(AM) 12	(AM) 13 Fontan: SPED-PV	(AM) 14 Freysdottir: SPED-PV-elem
(PM) Fisk, Gannon, & Whelan: OC	(PM) Schwab: NICU Follow-Up Thangamu: IFTP	(PM)	(PM)	(PM) Bjornsson: HIGH HOPES
(AM) 17 Schwab: SC-HFSC Fisk: ?	(AM) 18	(AM) 19 Gannon: PL 1 Retreat	(AM) 20 Sheiman: ADV Fontan: HVCC	(AM) 21
(PM)	(PM) Rindfleisch: Schwab: SPED	(PM) PL 1 Retreat	(PM)	(PM) Capraro: TM?

SEE BACK OF CALENDAR FOR CODE KEY

Times: AM sessions: 8:30 to 12:30; PM sessions: 1:00 to 5:00

For further information and/or directions call Christy Berr, UCONN Division of Child & Family Studies 679-4632.

Children With Disabilities Rotation

Name:

Type of visit:

Date:

Place of visit:
Phone:

Time:

Directions included:
Approximate driving time from Hartford: minutes

The contact person the resident should ask for upon arrival:

Prepare, attend, and reflect:

1. Review the material from the didactic session, component one.
2. Read the guidelines for this visit, located in the module binder.
3. Review the self evaluation.
4. Read any additional information to help you prepare for the visit.
5. Go to the visit, bring the guidelines, self evaluation, and the preceptor form.
6. *Give the preceptor the preceptor evaluation form.*
7. After the visit, fill out the self evaluation form and put it in Christy's box in 4H. (Be sure that all of your evaluation forms for the visits attended in that block are handed in *during* that specific block.)

Special Considerations and Extra Information:

If you need to cancel the visit for some reason 2 or more days in advance, please call Christy Berr (679-2350) and let her know. If you need to cancel the visit the day before the visit or the day of the visit (or are going to be late), please call the placement (phone number above) first to let the contact know. Then, call Christy Berr and let her know.

APPENDIX R

Court Case Used in Didactic Sessions

Cedar Rapids Community Schools District v. Garret F.

The Hartford Courant.
CONNECTICUT NEWS

Wednesday
November 4

PAGE 1
CT NEWS
LOTTERY
SPORTS
BUSINESS
EDITORIAL
OBITUARIES
CLASSIFIED
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PAST PROJECTS
ABOUT THE COURANT
ELECTRONIC LIBRARY

LATEST NEWS AP

Case May Define Roles In Schooling Disabled

By MICHAEL REMEZ
This story ran in the Courant November 3, 1998

WASHINGTON - A motorcycle accident when he was 4 left Garret Frey, now 16, unable to use most of his body.

Though Garret was left incapable of handling the most basic human functions without help, his mind remained intact.

His mother pushed to keep him in his Cedar Rapids, Iowa, school. At first, she paid for the extra help he needed - through a legal settlement after his accident - but five years ago Charlene Frey asked the school to pay for the school-day nursing assistance.

District officials balked, arguing that Garret's physical needs went beyond what they reasonably could be expected to pay. Garret and his family took the district to court. They won, both at the local and appellate court levels. Now the school district has challenged those rulings to the U.S. Supreme Court.

Advocates for school boards and children with physical disabilities - both nationally and in Connecticut - say they hope this case, set to be heard Wednesday, will help clarify the rules for caring for children such as Garret.

Though most children in special education programs have learning disabilities, schools are contending with growing numbers of students with severe physical disabilities. Medical advances have helped severely ill children survive longer and disabled children take part in routine activities more than ever before.

But who should pay for the extra services these children require?

David Larson, superintendent of schools in Middletown, said the court should draw a line that allows schools to take care of the educational needs of students with disabilities, while others - such as insurers or the federal government - pay for their medical needs.

``Do I think society should bear those costs? Yes. But I think there should be some other mechanism than using education dollars to do this," Larson said.

But Molly P. Cole, who runs the Family Center at Connecticut Children's Medical Center, said the top priority must be the education of the child.

``The bottom line is that child has a right to be in school," Cole said. ``If there are no other sources of funding, it falls on the school system."

Cole said certain programs are available to help defray the costs of special care, but when a student is not eligible, federal law requires the school to accommodate the child's needs. Otherwise, Cole said, that student is being illegally excluded from school.

The key issue raised by this case - Cedar Rapids vs. Garret F. - is whether Garret's care should be defined as ``medical services" or more routine services related to providing him with an education.

Garret is a quadriplegic who uses a ventilator to breathe. His daily care needs include feeding, urinary catheterization, suctioning his tracheotomy and repositioning him in his wheelchair. His family pays for a nurse who attends to him each night at home while he sleeps.

With similar circumstances, lower courts have issued conflicting rulings. That has led to calls for the Supreme Court to step in and end the guessing.

``Most of the time, these are terribly needy children," said Michael J. Wasta, assistant superintendent of schools in Bristol, who has devoted much of his career to special education. ``This does need to be clarified because it is an awful situation to put the schools and the families in."

Special education has become a fast-growing expense for local schools. Not only do schools face the cost of care, they also face more frequent litigation over just what their responsibilities are.

Wasta said for many school districts the calculation can come down to a balancing of the extra cost - whether officials think it valid or not - with the potential cost of a lawsuit.

``You count up the pluses, you count up the minuses, you look at your possible liabilities, and you make what amounts to a business decision," Wasta said.

The costs for each child's care can prove burdensome - especially in small districts - and take resources from educational programs, school officials say.

In this case, for example, Cedar Rapids estimates that Garret's care costs $30,000 to $40,000 a year for a licensed practical nurse.

The high school sophomore's family says that figure is inflated, because the district already spends up to $12,000 a year for a teaching assistant to help Garret. The total tab could be trimmed by hiring a single person capable of handling both health and schooling needs, they say.

The general rules for special education are set in a federal law, first passed in 1975, called the Individuals with Disabilities Education Act. The law guarantees that all children with disabilities - from mental retardation to physical ailments to learning disorders - have access to a free and appropriate education, individually tailored to meet a student's specific needs.

That education must be provided in the ``least restrictive environment."

In Garret's case, the lower courts relied on a 1984 ruling that narrowly defined ``medical services" - services schools do not have to pay - as those provided by a doctor. Because his care was handled by a nurse, Garret's was defined as routine care allowing him to make it through each day.

The school board and various national school associations say that definition is too narrow. Instead, they urge the court to adopt what they call a more ``common sense" definition of medical services that would include the intensive care Garret requires.

But Garret's family - backed by the U.S. Department of Justice - says that without those services, Garret would be deprived of access to education as required by the law. He doesn't need medical help for a worsening condition, but routine services to allow him to continue attending school.

Wthout those services, they argue, he would be consigned to homebound schooling and deprived of the stimulation provided by a classroom.

``You can't exclude those children from school," Cole said. ``We have to find ways to allow them to participate."

Email The Editor

SEARCHCOURANT

the Supreme Court has ruled! - Christy Berr

MARCH 04, 01:34 EST

Disability Ruling Impacts Community

By GREG SMITH
Associated Press Writer

CEDAR RAPIDS, Iowa (AP) — Garret Frey maneuvers through his high school hallways by blowing into a straw to steer his oversized wheelchair.

A nurse and teacher's aide are always at his side, looking after a daily care regimen that includes urinary catheterization, clearing his tracheotomy, monitoring blood pressure and responding to alarms on his ventilator.

The U.S. Supreme Court held Wednesday that the boy's school district must pay for his nursing care, a decision he called a victory for disabled students far beyond the halls of Cedar Rapids Jefferson High School.

``Everyone has a chance to have a free education," Frey said. ``It's going to help a lot of other kids. Not just me and other kids in Iowa. It's going to help all over."

But school administrators, while sympathetic to the 16-year-old's case, fear their new financial burdens could be overwhelming.

``There are 15,000-plus school districts in the country that are watching this case," said Lew Finch, superintendent of the Cedar Rapids School District. ``Where do you draw the line with how you handle medically fragile kids?"

Said Richard Ott, executive director of the North Dakota School Boards Association: ``We're already strapped. We can't do the things we're wanting and trying to do now. The costs of special education are mounting continuously, and if you even indicate that you want to examine them, you're accused of being opposed to kids with handicaps."

The federal Individuals with Disabilities Education Act provides that all children with disabilities receive a ``free appropriate public education." The 1975 law requires public schools to provide special education services, but an exception is made for medical treatment.

In Frey's case, the court ruled 7-2 that his continuous care during the school day is not medical treatment and must be publicly funded under the act.

The district has estimated the ruling will cost $30,000 to $40,000 per year in addition to the $10,000 to $12,000 now spent to provide Frey with a teacher associate.

The National School Boards Association estimates there are 17,000 students nationwide with severe disabilities. The financial arithmetic — conceivably running into the hundreds of millions — frightens the districts.

``Who is going to provide that money?" asked Sue Seitz, attorney for the Cedar

educA+tion

TOP NEWS

- **Disability Ruling Impacts Community**
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- **U.S. Department of Education**

Rapids district. ``So far the federal government certainly hasn't."

The federal government now pays about 12 percent of the nation's special education costs.

Leslie Seid Margolis of the National Association of Protection and Advocacy Services, downplayed the fiscal alarms sounded by the schools.

``There are kids with health needs who have had access to the services publicly without a need to battle for them," she said. ``Secondly, there aren't that many kids in this division so, in terms of numbers, it's not like the flood gates are going to open up."

Frey was paralyzed in a motorcycle accident when he was 4 years old. Until now, his family has paid for his care with money from a $1.3 million settlement with the motorcycle manufacturer.

``We are just overwhelmed," said Frey's mother, Charlene Frey. ``I'm very happy. It's been a long road and it's finally over. We've been anticipating this day for a long time."

Frey described waiting for the ruling as ``nerve-racking," but ultimately satisfying. It did, however, come down on a day the sophomore had to take a test and give a speech at school.

``I was stunned," he said. ``I didn't believe what they had said. Was it hard to finish that final exam after the news? Yes."

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AP

APPENDIX S

Didactic Session Satisfaction Comments
Module Session Satisfaction Comments

RESIDENT SATISFACTION WITH MODULE (ALL COMP EXPERIENCES)

DO YOU HAVE ANY SUGGESTIONS TO IMPROVE THIS MODULE?

add sessions to discuss experiences instead of filling out questionaires
add: talking to parents.
Again it would be better presented in a group format where discussion could be encouraged.
Again, shortening the forms, making them more relevant, and shortening the binder material
Already delineated in previous feedback.
Day care experience was a waste of time.
didactic done with Kathy, do not remember details need more visual/lecture style. neurology was not specific to disability children.
didn't need to have whole 1/2 day in adaptive equipment clinic.
do more audiovisuals
Don't schedule residents to NICU f/u clinic the day Dr. ? is there.
Good as is.
good selection of activities. EI program at home and school. would not omit/change anything.
I did not like NICU f/u visit because the attending doctor did not know my role there and put me to work medically.
I don't know. I do need to complete family visits which is an important piece of this module.
I had two daycare visits which could have been with something else.
I like more visual/lecture type of learning, mixed with discussion. did not like genetics session.
I think that the HSC visit would have been more useful if I had done more than rounding, visit was very medical, prefer to spend time speaking with educators, therapists about obstacles.
I think the entire module was well structured and very well organized. I woul love to have another opportunity to visit a patient at home or any other environment where he/she is getting a service.
If possible, more exposure to HSC maybe one day doing rounds and the next attending a team meeting or other activity involving the same PT at the hospital.
It might be helpful to see parents who are not so antagonistic to med field. I'm sure there are parents w/o axe to grind. Otherwise concepts good.
It would be good to get a community primary care pred 's point of view of how they care for a child with disabilities what things they find useful to do.
learn more about how to get from step 1-2;i.e. after finding out about ped's role in coord care, how does the ped determine which services are needed for particular pat. learning own limitations...
Make sure that visiting sites have good examples of children in EI. the day care I visited did not have any children actually diagnosed and receiving EI services.
Make the handouts a little more clear and consise so that they can be used as a quick reference when needed.
More case studies.
more discussion (with more sessions) would be welcome! perhaps less paperwork
More specific interaction between resident and DCFs staff i.e. post-discussion of observations, etc.
no comments
not sure.
nothing
Nothing, I was well-received and the visits were nicely organized.
Omit specialty clinic visit.
Omit visit to daycare center
One obs of an EI is enough and we don't need to see it to understand what is being done for child. I would rather spend more time with specialist like neuroto help us id children w/dis and learn from
Paperwork is lengthy, materials in binders could be more concise, alot is common sense. I get more out of direct observation and parent discussions.
Parents at didactic sessions was not helpful. At times it is not constructive, complaints about communication skills was due to personality rather than skills discussed in module.
Perhaps to review/discuss what learned adn re-connect information presented in didactics.
Potential to consolidate visits. Craniofacial visit and meeting was excellent.
shorten the evaluation forms.
Shorter post-test, shortened (abbreviated) written material
The community visits & home visits are great & really worthwhile. However, the didactics and paperwork really are still too much.
The didactic sessions shared be more interactive with several residents being present if possible to help encourage discussion.
The didactics was pretty straight foreward, perhaps shortening the lenght of the didac.session or using video to show different professionals - the ones we won't be visiting during the module.
The experiences are good. Would like to see the paperwork to be cut down adn the material in the binders more concise.
The NICU f/u visit was not particularly rewarding. I think htat we get most of this when we see families that we met in the NICU later on at CCMC.
The schools were very welcoming. It is hard not to be the focus of attention when you are a stranger in the classroom. I can't suggest any other changes.
Two sessions, ICC and Dept of public health task force.

WHAT WERE THE BENEFITS OF THIS MODULE TO YOU AS A PEDIATRICIAN?

Able to interact with school system which allowed me to specifically view the philosophy in practice. I now feel more prepared to apply the concept of FCC to my patients.
Able to observe children during OT at elem school. Saw collaboration btwn teahcher and therapist. Saw important issues during pulmonary clinic visit, transitional lifespan issue.s
Adaptive Equip clinic was great. Opportunity to talk with many different families, and learned alot from patient in clinic and situation.
Better understanding of needs of child and family
Exposure to difficulties families are faced with. Wheelchair clinic was great. Exposure is the greatest part of all of these modules!
Great for learning about available resources and when to refer.
Helpful to observe children iwth special needs in both mainstream and special ed classes.
HFSC visit was extremely valuable. Visits to other professionals allowed me to see exactly what was involved in their interactions with patients.
Home visit gave an opportunity to see effect of medical diagnosis on family's life
home visits were key to this module. A great learning and eye opening experience.
Home visits. Opportunity to see and talk with patients and families. Providing resources for us.
I do not remember this didactic. This didactic was done by Kathy.
I have a better understanding of audiology, rehab, and geneitc services when I refer patients to these services, I'll know what they can expect.
I learned importance of comm skills,how to use diff styles of commun. I value importance of communicating well with fams, & cultural diffs. Value supportingfamilies and oppty facilitate meeting.
I learned what each different professional does (i.e. OT vs. PT) also, the way they work together.
I now know more about rights of disabled children, IEPs, how the referral process for special education works, and more about providing education in the least restrictive environment.
I personally enjoyed and gained much info at home visits with therapists. I enjoyed home visits (to experience the environment children are living in.
I very much enjoyed my visit to Hospital for Special Care & seeing my friends there. My visit to speech & audiology was very useful as well.
I was delighted to see the preschool program and Rocky Hill as they function on atypical school day and I wish Hartford schools had same resources. HSC wa excellent exp. to learn concept of facil.
Information about these issues & insight into the way it works in Pennsylvania where I will do my fellowship.
Insight into the work of other professionals.
It allowed me to see first hand how childrn with disabilities are incorportaed into the early education system.
It helped to illustrate the patient's perspective and the need for a medical home.
It is always helpful to experience different types of clinical subspecialties. It helps to have a first hand idea of what goes on there, and when explaining the setting to a family.
It was beneficial to see the school system itself and how children with special needs are included and not included. Also beneficial to meet indiv. students and see IEP.
It was good to see what actually goes on during these sessions that I, as a physician, recommend
It was good to think of my own practice in a different light.
Knowledge about and insight into special ed in different settings.
More aware of special education services in school system.
Practical experience and exposure to children receiving Sped services.
practical experience and exposure to what other professionals do and how they can assist in team care of kids.
The home visits, community experiences and the clinics are the most useful part of this module. I love to be able to interact w/patients and families in different env. Learned from all the other profe
there were some amazing differences town-town, and home-home in the quality of services available. As a physician. I should be aware of these differences adn serve as an advocate.
This module has provided me tieh valuable insight into the frustration and needs of families. I feel more comfortable now in dealing with children and families with disabilities.
To me the best part of this module was that it alowed me to see how therapies are given to kids in the community vs. the hospital setting.
Understanding of FCC
Understanding of the EI process and opportunity to observe the intervention in process
exposure, increase awareness of services, w/ family problems, better sense of what to do to help and where responsibilities lie
To see what 0-3 does in the home, to see what they do in NICU f/u clinic.
It provided me with a better understanding of the role of the early interventionist and how to assist the patient's family in accessing these services.
It was very helpful to see what other disciplines do- PT/OT etc. and to see children interacting with these professionals. the Hospital for Special Care helped me understand thier needs better.
EI the field is centrally linked to Gen'l Peds and as such being introduced to its many facets will surely be beneficial to me the pediatrician in training
Exposure to what PT and Speech pathologists do in the home.
seeing special ed classes.
Seeing what programs are out there for my patients.
give me an idea of resources avail. and how to access them if needed and providing this information to families including psychosocial/physical/medical needs
I really found the home visit with the Speech Therapist the best part of the module. NICU f/u clinic was interesting except for the attending I was working with (wanted me by side not w/ therapist)

Once again it was good to see some of the therapies and evaluations we prescribe for patients. Often we just tell people to go for something and now I can tell them better what to expect.

learning about programs, laws inv. in early intervention and how accessible program was

Learning about 0-3 and IFSP. I do not remember details about the didactic.

It has reinforced the importance of coordinating services for families, as well as reviewed components to consider when working with families.

Understanding better what happens & how services are implemented once you refer. Can better explain to parents.

Learning about how different professionals interact together to provide services for an individual. also learned the importance of role release.

I got to see one of my patients at school , network with his teachers, nurse, and principal. I was able to get insight into the approach that educational profs. take in helping ch w/ dis.

The concept of early intervention is very dear to my heart as a future pediatrician. The most useful experience was to see the working result of making a referral to a program with EI services.

It was a great oppty to see how auxiliary services, how and what PT, Aud. do. Enhanced my undstg. of PT, Audio, and now I have a better understanding of parents exp. HSC visit was excellent

home visit interesting because M was in own turf and expert of situation. Opportunity share her concerns and gripes w me-something I might not hear in office. NICU fol up see later issues (abbrev)

Helped me become more sensitive to the needs of families with children with disabilities.

learning about options for family; support groups; and focusing on family and their needs in addition to patients. Learning about role of pediatrician in coordinating care

Practical experience/exposure to situations and children that receive EI.

To better understand the many people involved in providing education for children with special needs and the devices available to assist the student

It helped me to realize the importance of family oriented approach to management of a disabled child. I realized that this approach is very essential for successful of medical treatment.

exposure to theory as well as practice, increase awareness of problems and services available. and the practicalities re: my own practice

Better understanding of the limitations of current educational systems, buetter understanding of my position to advocate for my patients

Knowledge of resources available to obtain appropriate educaion for your child and also the importance of advocacy for your child

understanding how families adjust (emotionally/physically) when challenged with a child who has disabilities ie the psychosocial adjustments for parent andchild the med needs clinic home visit & freq

Not sure, thinking about my own communication style. Experiencing a good and bad PPT.

Adaptive equipment really opened my eyes to how wheelchairs work. I saw an example of excellent SPED (Tootin Hills) and "OK" (Granby) so it reflected real life I am sure.

better understanding of early intervention and pt rights to intervention

I gained a better understanding of what other professionals do ie: OT/PT, audiology, & how I can refer to them. Also what goes into ordering, adjusting & paying for adaptive equip (whlchairs/walkers)

It was interesting to see children withdisabilities, physical and psychological integrated into regular daycare settings

Learning, sadly, about the weakness of NICU follow-up clinic. Watching a daycare integrate a SPED child.

Now I have insight on what is available for children with special needs.

recognize that the family is the center for disabled children

Seeing what it is like for the family in a multi-specialty clinic & how many of their questions do not get answered.

Taught me how to be a better advocate for my patients.

To see a patient of mine receiving services in the home. Learning about parent perspective of B-3 & Spec. Ed. & coordinating care. HSC - Excellent!

Better understanding of when child receives speech services within school. PT @ CCMC, more professional and better equipt avail. Adaptive clinic, how expensive equipment can be.

To actually see physical therapy services that pediatricians refer children to often working correctly.

To see the social aspects of complex medical children/family needs.

Increased awareness of family's needs when a child in the family needs special care. My role as pediatrician was clearified.

An introduction to services available for children with disabilities.

Learned more about b-3 services and referal process which was very good

I felt more empowered about what I could do for my patients.

Helpful to see how teams meet PPT, also helpful to talk to family about their experiences.

I really feel that I have a better/deeper understanding of special education, and the visits to the two schools were excellent.

Opportunity to review roles of the professionals

Good examples of inclusive educational settings were observed.

It afforded me with a better understanding of the impact of interagency collaboration/service integration/resource allocation on family & children with special needs at large.

Further insights into the functioning of early intervention programs. Watch the intervention first hand. Important to see the resources available out in the community.

I gained a better understanding of the needs of the patient his/her family outside the hospital/clinic environment and gained an appreciation for the sometimes overwhelming nature of the doc vist

HSC visit was very useful to see patients receiving intermediate long term care. Seeing PT in different settings was educational.

I liked the EI visit and genetics visit. Not as much the Farmington HS visit, because I felt out of place adn the teachers didn't always know I was coming.

I enjoyed seeing the speech therapist from 0-3 in action.

nice to get into the schools to see how special education programs work. Helpful to have a framework in which to guide our patient's parents or understand better what services they are receiving.

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The best part of this module was meeting with a legislator, this demystified the experience and made it less intimidating to think about advocating directly through a legislator.

RESIDENT SATISFACTION WITH DIDACTIC SESSION

WHAT, IF ANYTHING, WOULD YOU LIKE TO SEE ADDED TO OR OMITTED FROM THIS DIDACTIC SESSION?

"Not sure"
?Nothing
a little less detail about the laws and more of an overview would be better
Add-experience of families who have been thru B-3.
Add flow sheet of basic building block of the influencial services.
Add glossary of terms and agencies. List of agencies and contact people.
Add more info about eligibility requirements for CT and other states in area. Omit discussion of past laws which aren't relevent to actions today.
Add: basic facts - who's who in EI in this region; different program providers talk of their role; concrete example of how process works
All important information
An example of how a family/child was helped to access funding
bathroom break; video tape: short cases with immediate feedback
Be certain to keep the element of a relevant parent included - for me this was the most valuable part.
Brief res on insurance problems and new legislation before the session-it was difficult to follow because not familiar with what's out there!
Case studies are very useful maybe we could experiment with using more cases to illustrate problems that families encounter when they interact with the state system
Case study is not necessary bc residents are very good @ getting pts diff supports-what to address-risk..Session is too long end @ noon b/c we have other resp to take care of bf clinic starts at 1:00
Cases were helpful. Good number of practical illustrations of information. I would not change number of cases.
Cases, short cases. Reviewing what families expect from their MD and what are the most ocmmon dificiencies in office visits from the family's perspective
Coffee Break
Continue to bring in someone from a different profession. ex. para, PT< OT< Nurse, etc.
continue with interactive sessions.
Could be shortened from 4 hours to 3
Could give out reading materials prior to the session so the session may be more of a discussion.
could we get a bathroom break halfway through the session.
Could we have the book ahead of time?
Definately keep parent aspect included.
Don't know.
Double sided photocopy = kill les trees!
excellent. no changes
family present
Fine as is.
good as is
good as is
good overview. Nothing
Great didactic. I liked that 3 of us were present.
Great session, thanks to Christy and Jill.
Great summarizing chart of plans, very helpful as a reference. ADD- who to talk to about plans like HUSKY a/b in each state?
Have the material available prior to lecture so we can come a little more prepared. Welll organized. Liked the small group comment & special guest. Thanks for the candy.
I'm a simple man and need simple instruction. Is there a possiblility to make a simple flowsheet on one page with Tel.#, addresses, different institutions?
I did not gain much from the meeting concerning upcoming legislation. Perhaps a brief overview of different programs available to patient (ie Title IX, medicaid) how one access would beneficial
I did not learn how to refer pts. to this FCC(other than that I should) I did not learn who are the contact people once a diagnosis is made. How can I as a pediatrician help?
I don't know.
I like the notebook organization.
I liked this session because it involved directly talking to a parent rather than just going over the binder material. Much is common sense so binder materials and tests can be shortened.
I often feel that one-on-one sesions work better than when local parents are also in our session.
I think having families present is a wonderful part of the sessions. They provide an important outlook as well as an adorable little one.
I thought it was great to have a child and mother at the session.
I thought it would be very helpful, perhaps if we discussed a real case and its effects.
I thought this format was very helpful in that it used my experiences to expand into the goals/objectives of the session.
I thought this session was perfect. We reviewed the reading material while incorporating examples from real life. The two people there to teach were excellent.
I would like a prepared way to access the schools for ages 3-21 support in school. Phone # of disability services or state representatives involved with this type of work.
IFSP video was kind of boring and we had already discussed everything on the video so it added nothing.

It might have been interesting to see some video presentations exemplifying & demonstrating living with disabilities.
It was concise and succint, no changes.
It was excellent!
It was excellent. Don't omit inviting a parent to the session.
It was great having two mothers in the session.
It was helpful to discuss my visit during the session - put things into focus/perspective.
It would have been more helpful to learn about teams in school where peds could be more helpful rather than focus on office setting. Examples of teams helpful. Nothing to Omit
Leave as is.
Longer sessions!
Make parts of the lesson more complete. Overall good.
Make sure to have a family with a special needs child in the session.
Maybe do some case studies to stimulate specific example discussions.
Maybe getting the folder of Early Intervention before session?
Maybe if the binder could be condensed even further with main highlights/points (Kara did a good job of summarizing key points though)
Maybe to meet with family involved in this module to ask more in depth questions.
Meet a family with disability (not available in this particular session)
More case based presentations could spark more discussion.
More interactive sessions with people involved in the 0-3 system.
More time
no comment
none
not asked - page missing
Not sure
nothing
Nothing should be omitted. I enjoyed the session. All the goals were met. I greatly appreciate the participation of other professionals. It makes the discussion very helpful and most of all enjoyable.
Nothing, fine session
Nothing, great examples!
Nothing. It was Great.
Nothing. Session was informative and pleasant and useful to me as pediatrician.
Nothing. it was informative, interactive and interesting. Thank you.
Overall a very helpful session. Will be a valuable resource for the future.
Perfect - except too much paperwork!
Perhaps a more detailed discussion of overall schedule.
Perhaps case scenarios of families with different socioeconomic backgrounds would more easily describe the different insurance options.
Possible that session became too example based on personal experience.
potentially participate & benefit their child together:I so appreciate this part of my training to give me these insights (& so do the children I may care for in the future!) (condensed quote)
Present more case oriented examples of principles. Omit the videotape.
Provide reading materials prior to session.
Providing examples of real life situations was the best way I learned about the law, rather than just hearing what the law was. christ was very effective in providing expamples as were the parents.
Sample IFSP perhaps include filled out sample form to see what actual documentlooks like
Situations that the family centered care would not optimally work and what might be done. ie.emergency situation w/ child in family of Johara Witness.
Some increased focus on laws/requirements from school systems.
Something to take the edge off.
Speaking with Molly was very helpful as a parent with a child with a disability even more so then being the director of the program.
Thank you for not going over the case study in the handout materials.
thank you for not showing videos. try to give case study/reading before session
The handout is very stron in this area. We'll see if having residents coordinate a team meeting for an inpatient would be possible.
The pretest because most of us haven't seen the legislation before this session it would be more useful to have a post-test, if at all.
The session seemed too long for the amount of material learned
the team approach only show welcome to my preschool and if time allows Hello, My Friends.
This was a great session- very informative. Thanks.
This would be hard to do, but if you could have the session at the legislation building and have time to go to a committee meeting or public hearing.
this would, as would others, be a good topic to have more htan one resident at a time to discuss varied experiences
Thought the session was well balanced. I particularly liked the video and having Lorna here to give examples of having a child with disabilities.
Try to make handout shorter, more concise (at least print on both sides) because the space for this whole program that I have at home is one big binder I am an intern and now have 2!!
Very helpful parents with disability kids clarifying practical issues.
Videos not helpful if talked about same material. More discussion - need more than one resident. This will allow for more input and experiences.
Videos should be used as illustration points and not as a substitute for someone knowledgeable about the material.
Was good summary of family centered care. Nothing to add or omit.

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We were a little pressed for time and could have had more time to discuss the video and personal experiences.
Went well. We all shared our experiences with communication and team approaches
You gave me a lot of info in 3 hours- I hope I can remember it.

WHAT ARE THE BENEFITS OF THIS SESSION TO YOU PROFESSIONALLY?

A better understanding of the goals of team based services. My role as a pediatrician is more clear.
Able to better understand services available and laws in place for individuals with disabilities
Able to gain the perspective of a mother who's son has several problems.
Again, this kind of module can only benefit the pediatrician who shoudl be integrated and participating in all such aspects of teh care and progress of his/her patients.
Allows me to better understand what each provider's role is.
As a future pediatrician it is imperative that I learn about various resources and agencies.
Awareness of available programs for early intervention.
Becoming familiar with laws pertaining to special education/inclusion
Becoming more knowledgable about the laws and the details about early intervention services to allow me to be a better advocate for my patients with disabilities.
Being able to advocate better for the patients.
Being armed with information re:services, funding that I can share/use with families in my practice.
Better understand roles to facilitate discussion.
Better understanding of interagency collaboration
Better understanding of special education facilities and availabilities.
Better understanding of teams inter, multi, trans and the roles of the players
Better understanding of the disability longitudinal.
Better understanding of the process through which children become involved in special ed. I also feel this knowledge will assist me in providing parents w/guidance as their child enters school system
Better understanding regarding laws affecting special education and how physician can help advocate for patients who need special education.
Breaking down the elements of effective communication and teamwork adn reflecting on my own style.
Clarification of funding and eligibility criteria
Clarification of goals and learning how team must function to affect change. Learning skills which make a team function more effectively.
clarification of the roles of healthcare providers to the education and medical needs of children with disabilities.
Clearer understanding of team management, my role in them.
Clearer understanding of the roles of professionals and team based models.
Description of Team meetings involving schools-good examples vs. bad examples
Discusion with the family about own experiences allow clear illustration ofhte concepts and will remain reinforced and more readily availale for clinical use
Excellent overview & lots of info given about Birth to Three that I was eager to learn.
Expanded on my previous knowledg of early intervention
Familiarization with early intervention, birth to three referral process, adn services offered.
Gave me a better background of the legislative process. Gave me new ideas of easy ways to advocate for children.
Good summary of information about laws and how we as physicians can play a role.
Got info from Special Ed. teachers and parents as to what they want to see from their pediatrician.
greater insight to my role as a pediatrician and understanding the different team approaches
Help me to be able to meet the needs of children with disabilities and their families
Helped me to have a better understanding of the laws, b-3 and my role in the process
Helped me to know some of the available services for children and the law on which they're based
Helped me to learn about the resources available to my patients and how they are organized. It also provided a thought process and different approaches to meeting a child's needs.
Helpful hints about how to work on my communication skill.
Helping me understand funding and barriers of obtaining funding for families- impact of finance on families with disabilities
I am very happy to have learned more about the importance of agency collaboration and also about the funding programs available and how they need to work together.
I have gained knowledge-nitty-gritty (detailed to some extent) of the legilative process. Will definitely use to manuver in future for pursuit of legislative interests.
I learned basics of funding so that I can help my patients and parents in my practice
I learned more about funding available for disabled patients.
I was happy to learn about hte laws in place in CT for children w/ disabilities. It was also helpful to learn how families get involved in EI and what my role is. Very helpful to have Jill here.
Increased awareness.
Increased my knowledge about available services and taught me my role as a PCP.
Information is always beneficial.
Information on resource allocation.
information; guidance to help patients; insight on resources to help families; talking w parents and learning about their views and expectations of a PMD and how they can advovatey
Insight into al of hose other aspects of the care of the child with disabilities that mke their child's attainment of his/her potential truly possible, and how that happens.
Introduced to me to the laws that protect and provide support for kids with disabilities.

Introducing us to services available to children with disabilities.

It allowed me to learn about birth to three and how to access it. In the future I can use it as a resouce.

It allowed me to learn more about the laws as well as to learn more about the proces of referral to special education.

It allowed me to understand what the family care center is and how touse it as a resource for my patients.

It allows me to understand the difference between multidisciplinary , interdisciplinary, and transdisciplinary. Info that I coudl use to help my patients.

It makes an excellent introduction.

It will help to advocate for my patients and encourage and educate parents about how to advocate for their families.

It would help me to view the patient as whole including seeing the social and family perspective and not only the medical illness.

Just to hear personal experiences and that the advocacy we do is not the standard of care.

Knowing resources available to patients. Understanding the process of evaluation and planning for each child and how MD's can participate.

Knowing resources for families.

Knowledge of resources available to families. Obatacles that are a part of our current system are more clear.

Knowledge of special education. Provided me with 3 hours of enjoyable popcorn and intellectual conversation

Learn more about laws and special education services provided.

Learned how to influence changes in law to benefit my patients.

Learning about health care funding.

Learning about teams and how to be an effective leader.

Learning how to collaborate with B-3 services where needed; understanding their team approach

Lets me know th difference I can make as pediatrician to help with safety/well being of children outside my practice.

Necessary information for pediatrician

New perspective. Education me to a "new field" of medicine

not asked

Not asked

Opportunity to interact with Early Interventionists-people to whom I have/will be making referrals. Allowed for a better understanding of their philosophy.

Orientation to services available to families with children w/ special needs for use during my residency and beyond will certainly benefit my pts and enhance my services to them.

Probably more helpful to me than I realized at the time because since this session I have been able to visualize my patients situations better and at least ask relevant questions.

Provided me the basic information I need to be albe to screen early intervention

Provided one with understanding of special education

Remains to be seen. Should help in cross-disciplinary understanding.

Seeing actual children in special education role and the benefits and limitations of such services.

Sparked my interest in the value of coordinated team approach in the care for children with special needs.

The benefits are that after this session, I am better able to understand the importance of a transdisciplinary team in early intervention services.

The importance of communication.

the info id ke re: insurance reports, services, what's eligible, etc. I can now help a few of my families by directing them to the proper resource.

There are services I eill be using and it clearly helps m=to understand how to refer and to what I'm referring to.

This session provided me information/understanding of my patients rights and how they are enforced. Very useful to meet with parents of children w spec needs and have context for what can do as doc

This session would help me in evaluation & follow-up of children with special health care needs.

This will help me to better advocate for my patients who need services within the educational system. By knowing the law, I can help families to know the law and get services for their children.

To be honest I'm not a legis lawyer yet I must know about what I can expect for my patients, but I found it boring to listen to law related info w/out placing it into case contact.MORE CASE RELATED

To explain what constitutes an appropriate special ed setting. To review the importance of placing child in least restrictive environment. To review the types Sp Ed resources available in CT.

to help me to know all the different ways I can advocate for parents and families.

To know what laws about disabled children you can draw on for resources as well as organization that exist.

To learn about the different types of teams was useful to learn so that I can interact effecitvely with teams in the school system and in the hospital.

To provide me with knowledge to be able to help parents know their rights.

To review and teach about the early intervention programs and resources available to patients in Connecticut. Review the impact of early intervention programs on development.

Understanding patient family stress.

Understanding roles of professionals that may be caring for my patients. Understanding what happens after I make a 0-3 referral.

Understanding the various rules that professionals play in a child's care.

Understanding transdisciplinary approach & how the professionals interact with one another.

well thought out session

What is available to me as a PCP.

Will help me consulting families on their rights for medical help.

not asked

Better informed re: early intervention B > 3

It ws good to learn more about the services we prescribe for our patients.

It would help me to understand the referral process for B-3 and working of the system..

Who to contact and what a child is entitled to.

Introduced a concept which when integrated into my practice will lead to the provision of care in a more "user-friendly" way.

Clear, practical introduction to Early Intervention

Providing info on Bto3. Some of the ? leading up to the program; the different components

Very informative practical based. Imp to know laws

Understand what services are available; how to access them; limits and benefits of each plan

First meeting when I was actually interested and felt I learned something. Able to pull in last years sessions (IEP, IFSP, PPT stuff) to organize this session

Good to know compassionate/helpful org. out there. Made me more aware of the challenges fams face and will hopefully make me more sensitive to these needs in the future.

Helps me to understand the law and the state programs in place to assist children with disabilities so that I can effectively refer children and help coordinate their services

Learning res that are avail for my pts fams. Hearing the exp of Nathaniel's mom @med prof-what interactions were +,- how could they have been different?

Very helpful in learning about components of teams. How an effective team can be set up. All important background inforamtion for connecting a team or being an effective member of a team in practice

Knowing available resources, empathy, learning terminology, understanding the goals of the course...big picture

I got a clear picture of the roles of various professionals involved in teh care of a child with special needs. It was useful to learn about the differetn models of therapy.

Learning about laws related to special education

Better quality of care for patients

Enables me to speak with patients and parents Re: 0-3 services available. Will be able to better understand what families w/ children w/ disabilities are going thru when involved in 0-3 programs.

Understanding parents perspectives, understanding the importance of communication, knowledge of giving bad news, listening to parents.

I learned about transdisciplinary, role release, adn role of MD, excellent.

Provides knowledge about the current laws and Birth to Three process to better advocate for my patients.

Parents are always asking insurance questions. I feel more comfortable answering.

to hear what parents of children with disabilities had to say aobut the health care system its function and services so I could better prepare myself to ...their ideas

not asked

crystallized all the fragmented info I've been given over the past couple of years regarding B-3, spec ed, etc

good to see the different ways of integrating kids into special ed and regular classrooms

Having done a lot of work with teams even before this, it was good to get a feeling for the way things should go. (also reassuring to realize that mine had indeed gone pretty well)

good to learn about laws, role of school in providing concrete objectives, plans

samples - leter to a legislator, letter for SSI

Clarification of my own role as well as the roles of others.

Important to learn about laws, different plans.

not asked

I have never been introduced to the concept of family centered care

I came away understanding the importance of Family Centered Care Model and the need for financial, emotional, and medical support. I did learn how to deliver

More familiarity with the laws behind special education and physician's role.

Will make more sensitive to parents' concerns about their child, about the role I can play at PPT meetings, etc, about being an advocate. Learned better about role of physician at team meetings.

Preparation for future intervention into the legislature.

Very good opportunity to clarify professional roles and how they are best incorporated into approaching the care of a child. Good intro as to how a child is introduced into a program and develops

Helped me to understand the process of team meetings and how to use them to help my patients and their families.

Better understanding of B-3 How and why referals are done. What my B-3 pts are receiving for services: what my role is in EI, IFSP, etc.

know more about how to advocate for patients legislatively.

Having the opportunity to share with a parent and her children their experiences as well as their vast knowledge of the system was the best part of the didactic.

I will use the skills from this session in many areas in my professional and personal life.

Important to Learn about team process before attend (PPT). Important aspects of team, roles of others, and dealing with conflict.

Understanding what's out there and how to get connected.

I know whre to access legislative advice to help a patient

Reinforce my knowledge about my role as a primary care doctor.

To learn more about the higher structure of services provided to children and how those agencies collaborate and what impact that has on families was helpful.

Becoming aware of the services that are available to my pts. Better understanding of Birth to 3

We see kids who need sp ed frequently and so there are alot of practical applications

Showed me options available to children for integrating medical and social needs together.

Information about the Family Center and the services it provides

I have a clearer understanding of the various team based models and what the role of various professionals are.

To implement the services to the needs of my patients.

Tremendous benefits

Clarifying different arrangements for team collaboration and better understanding -service provision/role release

Better understanding of the laws and how to advocate for individual children and for children in general

Clearer understanding of partents expectations & how they look at the pediatrician as center pivot.

I know more about:1)rights of disabled children 2)individual educational plans 3)how referral process for special education works 4)providing education in the least restrictive environment

Prof taking care of child with spec needs I'm not alone.There are res available to empower fams rather than to make them dependent on the system; to help them attain lives close to "normal

Requirements as an M.D. in IFSP and how I can help my future patients with disabilities and their parents

Better understanding of my own role and responsibilities as well as what families face, and the political aspects of services available

Being able to approach complex issues at different points of view depending on expertise.

Organized many different ideas/services into one easy to understand packet and discussion.

To learn how to appropriately participate in a team as well as facilitate a team. Taught me about my own communication skills & how to interpret communication skills of others.

Provide me with information to approach collaboration and funding issues in Indiana where I will be practicing

Comm Skills are probably the most valuable as a physician and this is 1 of thefew instances I have been taught about them. Learn directly from parents of child w spec needs about relation w ped.

Very valuable info regarding the laws and how they are applicable to specific families. I am more knowledgeable about services available to my patients with special needs

I am more aware of services available, and of my own role responsibilities

To be aware of services available. Orientation to FCC

Helps me understand what financial resources are available to my patients.

Good resource presentation.

A session like this can only benefit a pedi resident in training b/c there are few forums to have an opportunity to understand what it takes to coordinate care for a CSN & to bring all those who could

Provided info/sources of info relevant to patient care. Gave good specific indication of how to approach helping families coping with disabilities

Better understanding of the laws and how to advocate for my patients.

Understanding how and when to refer for early intervention and what is available

Helps to realize the importance of including family in decisions. Realizing how it is for families to understand their children. And for us to understand the difficulties they go through.

Gave me an opportunity to see what schools/communities/insurances are mandated to provide to complex medical children

Allows me another perspecitve and a way of looking at families and issues to discuss with families and caretakers of disabilities.

Good intro to insurance and funding issues.

clearer understanding of law and its effects on medical practice

Understood B-3 referral process much better also eligibility criteria

The info provided

Familiarize to the legislative process what my role in lobbying could be.

It was good to think about better ways to integrate servcies for my pts. Also good to start thinkin gabout funding issues.

Excellent intro.Very exicited about this elective now that we have discussed the goals & obj. Help to orient me to beginning of health care from family's perspective & fam is constant caregiver!!

Help in clearly understanding EI referral and role of pediatrician in referral and IFSP program. I will be better able to refer my patients and follow-up appropriately.

good learning objectives. Clearly and consisely stated. Good vignette and discussion. Very informal, easy to ask questions, state opinions.

To review the importance of inidvidualizing care plans with a family. To remind us to explore broader range of issues in the home setting that will influence multidisciplinary care plans.

Having parents available to share personal experiences. Overall explanation of family centered care.

Understanding and awareness of what types of issues families w/children w/disabilities deal w/& learning a rational personalized approach to provide resouces and care for these individuals

Help me organize my approach to communication with family and other professionals; improved my understanding about the team approach

Understanding how family support works with how I can utilize it. Understanding these families' unique perspectives

Appendix T

Resident's Closure Session Form
Resident's Closure Session Themes

Closure Session

Resident Name: ______________________ **Date:** ______________________

Facilitators of Session: ______________________

Items for discussion

1. Where are you going after residency is completed?

Fellowship: In: __________ Town: __________ State: __________

Practice: Town: __________ State: __________

Chief Resident

2. Review resident visit sheet

First Year

*What did you like about the first year of the curriculum?

*What did you not like about the first year of the curriculum?

*Give one example of how you have applied the information you learned in the first year of the curriculum.

Second Year

*What did you like about the second year of the curriculum?

*What did you not like about the second year of the curriculum?

*Give one example of how you have applied the information you learned in the second year of the curriculum.

Third Year

*What did you like about the third year of the curriculum?

*What did you not like about the third year of the curriculum?

*Give one example of how you have applied the information you learned in the third year of the curriculum.

3. Name 2-3 things that stick out in your memory about the whole rotation.

4. In relation to the whole rotation, name 1 thing that you would change if you could.

5. Do you have any final questions about the rotation, any patient related matters that we could help you with?

6. Would you like to review your file? Yes No

7. Self Evaluations Missing

8. POST TESTS to complete

9. Module Satisfactions to complete

10. Annual evaluation reviewed? Yes No

Additional Comments/Notes

Physician's Training Project

Resident's closure sessions: themes

7/5/00

First Year Curriculum.

Year 1, question #1: What did the resident like about the first year curriculum?

Systems—Residents felt that learning about Early Intervention made them more aware of the system. It made referral easy because they knew how to access the system, and it made it more likely that they *would* access the system. They felt very comfortable explaining to parent's what they could expect from B-3. "It was good to see what happens when Birth-3 goes out to the home. (From this) you can tell your families what to expect" (when you make referrals).

The Classroom— Learning about special education and actually visiting the classroom allowed residents to see what was involved with special education and how children with special needs can fit into the system. Residents liked observing how special education works in the classroom. "It was good to see what's involved with these kids—because I didn't know and we see so many of these kids (needing special education).

Laws—residents felt it was very useful to know the laws of Early Intervention and Special Education. Knowing what a parent's rights are, and being able to advise them of their rights was important.

Community visits—Observing children receiving intervention in the home was important. Residents felt that it was interesting to get insight into what the family endures. Also enjoyed seeing first hand what a therapist does in the home, and seeing "what a typical afternoon was like" in a home where there were multiple children with special needs. One resident commented that "It was a bonus to see the providers (Early Interventionists and Special Educators) doing their jobs. The experience, although brief, in these placements helped me to get a real feel for it."

Year 1, question #2: What did the resident *not* like about the first year curriculum?

One-on-One Didactics—the resident's strongly disliked this set-up. They felt "put on the spot." They felt there were not enough people to hold a good conversation, which made the didactics difficult to sit through and seem long and cumbersome.

Year 1, question #3: Can you give one example of how you used the information that you learned during the first year?

Referrals—Residents informed parents what can be expected from the evaluation, the process, and the development of the IFSP. All the residents felt comfortable referring to Early Intervention. Residents felt that they were better able to identify families who could benefit from services. Residents also made successful referrals to the local Board of Education for children over three years old.

Helping Families—Residents informed parents about their right to request a PPT, and what a family can expect from an IEP. One resident commented that "whenever I had a patient with any problems I felt more empowered to advocate for the children. I made phone calls to one child's social worker to get the child moved to a school closer to home. So I have been much more involved and much more motivated to do it." Many residents contacted schools and teachers on behalf of their patients and families.

Second Year Curriculum.

Year 2, question #1: what did the resident's like about the second year of the curriculum?

Respecting Other Professionals—Residents liked learning about other professional's roles and backgrounds and gaining a better appreciation for what they do. One resident commented that he gained a 'new respect for therapists." He "got to see them interacting with the patients and seeing the patients not only enjoying but benefiting from the therapy."

Communication—The residents felt that the experience reinforced the importance of communicating as a team. "Seeing the team meeting helped me to know how it works, so that I know what my role is as a pediatrician on that team." Another commented that this "sharpened my skills and reinforced the importance of communicating as a team." I "learned about the importance of communication between all the professionals involved with the family."

Family's Perspective—Residents had a better appreciation for the family's perspective of the specialty clinic visit and of the services available. Found it enlightening to experience the clinic from the parent's point of view. "Mom was great. She knew what her role was in showing me the parent's perspective. Sharing her concerns and watching how little of her concerns were addressed. Amazing experience; very comprehensive and enlightening."

PPT—Residents were able to see who comes together, and what it is that can be done. Learned what the physician can do in a PPT meeting. "Seeing the team meeting helped to know who and how it works, so I know what my role is as a pediatrician on that team." "PPT was great. I got to see what people come together and what they do. It was very useful."

Year 2, question #2: what did the resident *not* like about the second year of the curriculum?

Everything was fine—nothing disliked (yes, this was a theme).

Theory vs. Reality—Roles, Teams, Communication Skills—residents felt that while theory and ideal are fine, the ideal doesn't happen in practice. Some felt that they spent time learning ideals that they won't be able to apply.

Year 2, question #3: can you give one example of how you applied the information you learned in the second year?

Expectations—able to tell families what to expect during a specialty clinic visit. Able to explain what would happen in a PPT. What it would be like, and who would be there. Residents now know what will happen to their patients and families when they make referrals. "When I referred a family to audiology I was able to communicate to them what to expect."

Communication—Knowing what a professional's background is helps in communicating with that person. Residents know what to send in with parent to the PPT if the resident/physician cannot personally be there. (These modules) "helped me be a better team player."

Supporting Families—Residents feel more able to support the families in their practice. "Knowing the feeling of how overwhelming it is and being sensitive to that…taking extra time to answer questions—and being accessible to answer questions." "It's a comfort to myself (to be able to support) families in my practice." "…so parents feel they have the backing of a physician in the meeting."

Third Year Curriculum.

Year 3, question #1: what did the resident like about the third year of the curriculum?

Advocating for patients and families—Residents feel that it is much less intimidating to advocate after spending time with the AAP lobbyist at the Legislative Office Building/Capitol. Residents are less anxious about testifying after seeing how the politics work up close. Watching the proceedings made the residents want to be more active at the systems level. "I could see myself doing that (testifying) and watching them made me want to be more active." "I really liked the advocacy part and going to the Capitol—what kinds of things are going on, who are the players—helpful to see because you can not only advocate for your patients, but it will help me support my patients in advocating for themselves."

Administration and Funding—Interviewing an administrator gave residents an appreciation of the difficulties being faced. "My talk with the man at Medicaid gave me a better appreciation of the difficulties in providing adequate medical care to this population (of Medicaid patients) and they aren't doing such a bad job of it." "The funding issues were the most interesting part—learning about additional funding for families with kids with special needs and learning about family's frustrations with the system." "I learned to see the Dept. of Public Health ...from the other side." Some residents found it helpful to learn how different the system is in another state. These were the residents who conducted a telephone interview with an administrator from another state because s/he was going to practice in that state after graduation. "I liked interviewing the Early Intervention Administrator in New Jersey, because it was interesting to hear how different the system is in that state."

Year 3, question #2: what did the resident *not* like about the third year curriculum?

Everything was fine—nothing disliked (no other themes present).

Year 3, question #3: can you give one example of how you applied the information you learned in the third year of the curriculum?

Helping Families Obtain Additional Funding—residents have written letters to various agencies in support for extra funding for their families.

Advocacy—the advocacy projects helped residents become more involved with the community, and more politically involved. Some wrote letters and made phone calls to congress regarding issues important to their patients and families. One resident is thinking about beginning a therapeutic horse-riding program for children with disabilities after exploring this topic for her advocacy project. Another resident researched and then designed an information brochure on the Florida Early Intervention system, so that she will be able to distribute it to her families when she goes into practice in that state.

Resident's Impressions of Overall Curriculum.

Overall impression, question #1: can you name 2-3 things that stick out in your memory about the entire rotation?

Community Visits—residents got a better sense of the parent's perspective, and these visits gave residents new insight into classroom inclusion. "If people have the right attitude about inclusion and value all people, it can happen. It made me hopeful." "I know that nothing about sitting with the family in my office could replace going to the school and seeing the kid (in the classroom) and talking with the teacher." This "increased (my) awareness of family issues that are not medical—shaped my thinking—where else would I get information to help families with the school system—with birth to three?" "She (mom) explained things to me (that) she would have changed about her interactions with providers—that was helpful for me."

Going to the Legislative Office Building/Capitol—learning about the legislative system. " The Capitol visits were so different than what I have ever done, really neat stuff. Gives you a realization of potential ways to advocate at the legislative level...before I would have undervalued my input and now I value my input and letting legislators know." Of all the evening seminars, residents enjoyed the legislative evening seminar with the mock hearing best.

Advocacy Project—made "everything come together" for medicine/pediatrics residents. Learned where med/peds physicians can have a special role for people with disabilities as they transition from adolescence into adulthood. "Good to see how transitions should be made...actually seeing all the specialists together talking about how important the need is." "My advocacy project—the transitional meetings I went to really made it click...we need people to bridge the gap and med/peds can do that...these kids who become adults need you." Pediatric residents also voiced satisfaction with their projects. "I liked learning to work with organizations to get funding," and "I liked learning how horses can be used for therapy."

General Comments about the Rotation—residents liked the rotation's flexibility and the tailoring of experiences to the resident's interests. "This flexibility has increased the flexibility I have when working with my patients and their families—teaching by modeling—being flexible." They also feel that changes were made over the course of the rotation as concerns were raised regarding certain elements of the curriculum: paperwork/redundancy/didactics—"everything I wanted and asked for has been changed over the course of the 3 years. This has been great to be able to have this kind of input and impact!"

Overall impression, question #2: In relation to the whole rotation, name one thing that you would change if you could?

Paperwork—too many open-ended questions. Too detailed. Residents would love not to have the paperwork, but some understand the necessity of it.

Redundancy—home and school visits and didactics were too many in the beginning.

None Now—changes have been made. "We have evolved so much since we started."

Appendix ~~XW~~ a
Post Residency Survey
Post Residency Survey Themes

APPENDIX V
Hartford Courant Article

APPENDIX U

Hartford Courant Article

Hartford Courant 10/15/98

Linking Up For Students

UConn-Schools Collaboration Expanded

By WARREN WOODBERRY JR.
Courant Staff Writer

ROCKY HILL — A collaboration between Rocky Hill public schools and the pediatric division at UConn Medical Center has been expanded to meet the needs of students with disabilities at four district schools.

As part of the center's three-year residency training curriculum, Children With Disabilities Pediatric Rotation residents are observing school programs at Moser, Stevens and West Hill elementary schools and Rocky Hill High School.

The collaboration — which began last school year at Griswold Middle School — will allow residents to learn about the educational issues of students with special needs, and to see how the school system adapts for each child. In turn, district instructors have been invited to participate in pediatric seminars and workshops.

ROCKY HILL

"I think one of the best services we could do for the children in the school district is to have excellent communication between the medical community and the school," said Ann Milanese, medical director for child development at the Connecticut Children's Medical Center and also medical adviser for Rocky Hill schools. "The program encourages communication. In the end it benefits the children."

District special education director Patricia O'Connor said the observations will help residents make confident decisions once they become practicing pediatricians.

"Often times recommendations aren't exactly doable. If you're not in the public school and see the setting it's hard to give a correct perspective of what's going on with a child," O'Connor said. "Residents will discover what they can recommend to parents for their kids to stay in the mainstream."

UConn project director Mary Beth Bruder, said residents are "not just looking at these children as patients but also their family, the school system, child care and their communities."

Bruder said about 10 residents are participating in the district.

Appendix V

Post Residency Survey
Post Residency Survey Themes

762

Division of Child & Family Studies

Post-Residency Physicians Survey

Name of physician being interviewed:____________________________________

Preferred contact number:__________________________________

Hi my name is__________. I'm calling from the Division of Child & Family Studies at UCONN Health Center to follow up on the Children with Disabilities Rotation. Eileen Fisk has sent you a letter regarding this telephone interview. The interview will take approximately 15 minutes. Are you interested and willing to participate, and is this a convenient time to talk?

Not willing to participate_______(check mark)

No_________When would be a better time? Time (and day?)______________________

Yes_________OK, great, lets get started!

First, a few questions on demographics:

1. Did you graduate in 1998, or 1999? (circle one)

2. Are you in practice or in a fellowship program? (circle one)

<u>If in fellowship</u>:
3. Where is your fellowship program located? City____________________
State______

4. In what subspecialty is your fellowship? (write-in, or circle one) _______________
Cardiology neurology adolescent medicine infectious disease
G.I. neonatology rheumatology development pulmonology
Genetics

<u>If in practice</u>:
5. Where is your practice located? City____________________ State____________

6. What is the approximate size of your practice? (write-in number of patients)
____

7. How many pediatricians are in the practice, including yourself? (write-in number of pediatricians, total) ______________________________

763

Now we come to the questions on children with disabilities and their families: There are 1-3 questions for each of the 7 modules of the rotation.

The first module was Family Centered Care. In this module we discussed the 9 principles of Family Centered Care, the importance of cultural competence, Family Systems Theory, and the Medical Home Model of caring for children with special health care needs and their families.

The underlying premise of the 9 principles of Family Centered Care is the development of a system that:

1. Assists in the delivery of services to children with special health care needs, and
2. Supports the needs of the family

We know that practicing family centered care can be a challenge in a busy office setting.

8a Please tell us about one visit, or one family, where implementing family centered care was challenging:

8b Please tell us about one visit, or one family where implementing family centered care was easy:

8c. What made it easy?

9a. Do you have any patients receiving Early Intervention (Birth to Three) services? (circle one) Yes No

9b. If yes, how many of your patients are receiving Early Intervention (Birth to Three) services? (write-in the number)______________________

10a. Do you have any patients receiving Special Education services through the school system? (circle one) Yes No

10b. If yes: How many? (write-in the number)____________________

11. Have you, personally, made referrals to Early Intervention since you have been in practice or fellowship? (circle one) Yes No

12. Have you, personally, made referrals to Special Education Services since you have been in practice or fellowship? (circle one) Yes No

13. Have you reviewed any IFSPs (Individualized Family Service Plan) since you have been in practice or fellowship? (circle one) Yes No

14. Have you reviewed any IEPs (Individualized Education Plans) since you have been in practice or fellowship? (circle one) Yes No

15. Have you attended either in IFSP or an IEP since you have been in practice or fellowship? (circle one) Yes No

16a. Have you interacted with Early Intervention (Birth to 3) providers or the school system in other ways, such as by letter or telephone? (circle one) Yes No

16b. If yes, in what way? (write in the answer)______________________________

____

____

17a. What do you remember about the Early Intervention Module that made it easier for you to serve your patients who are receiving these services?

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17b. What do you remember about the Special Education module that made it easier for you to serve your patients who are receiving these services?

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18. In what way has the information you learned about occupational therapy physical therapy, speech therapy and audiology useful in your work with patients and families, or in your work in the community?

____

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____

____

19a. Since you have been in practice or fellowship have you personally given families information regarding agency resources and/or public sources of funding,

(circle one) Yes No

<u>examples:</u>

Dept. of Mental Retardation
DSS
SSI
Medicaid
WIC

19b. If yes, which agencies or sources? Any additional?

____

____

19c. Do you feel comfortable making referrals to these agencies?
(circle one) Yes No

20a. Do you sit on any boards or committees that serve the welfare of children?
(circle one) Yes No

20b. If yes, which boards or committees?

____

____

____

____

21. Can you please give me an example of an interaction with a state agency or insurance company where you have advocated on behalf of a child with disabilities? (write-in the answer)____________________________________

____

____

____

<u>if unsure, these are examples:</u>

Coverage for special equipment—wheel chair, bath chair
Nursing coverage
Extra funding through Social Security, DMR, etc.

22a. Have you advocated for children at a systemic level; **(pause)** for example, attended or testified at a legislative hearing or wrote a letter to the editor of the newspaper regarding a pertinent issue? Yes No

22b. If yes, how did you advocate at a systemic level?

____

____

____

____

23. As you reflect back on all 3 years of the curriculum, if you could change just one item, what would it be? (If the answer is "paperwork/forms," ask if there are any additional).

____

____

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24. Is there any other information you would like to share with us about the rotation?

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That's all the questions. Thank you for your time.

Post-Residency Survey: Themes from Open-ended Questions

Question # 8a
Please tell us about one visit, or one family where implementing family centered care was challenging?

Communication: Situations in which communicating with the family was difficult made implementing family centered care challenging. "Nine year old boy who was deaf & had behavior issues...communication barriers because of sign language and Spanish as the primary language at home. Mom spoke some English, but it was difficult to communicate—especially directly with the boy." Sometimes the communication problems exist because of social issues "Little girl's father was not around and she was fatally ill...it was difficult not to be able to work with everyone in the family."

Insurance: Lack of insurance, or insurance limitations, make implementing family centered care challenging. This can be frustrating for both the pediatrician and the family. One example given was of a family with "Twins with cerebral palsy. A lot of issues and difficult insurance coverage so family was constantly fighting to get what they needed."

Parent's intellectual capacity: When one or both parents have limited cognitive abilities it can make implementing family centered care difficult because "it makes it difficult for her (mom) to effectively advocate for her child's needs." A pediatrician who was new to the state where she was practicing commented that it "required me to find resources for the parents as well as the patient."

Social issues: Social issues permeate the practice of pediatrics and they make a large contribution to the challenges of implementing family centered care. Among the problems were: "patient living in shelter was uncomfortable having providers come work with her." "Young parents who don't have resources or (have) limitations with insurance or support." "Foster care involved which changes very often so there is no consistency of care."

Question 8a & 8b: Please tell us about one visit, or one family, where implementing family centered care was easy. What made it easy?

Knowing the system: Whether it was that the family was familiar with the system, or that the pediatrician was familiar with the system, this made things much smoother all round. "Knowing the options...and teaching families they don't have to go to PT office 2 times/week, but can do it themselves or have it done in their home." And, a "Foster mom already in B-3 who was able to have service providers see both kids together." And, " Because I'd worked with the family as a resident, it's been easy to access resources and get consistent care."

Family has supports: This makes implementing family centered care easier because "Families with resources, money and support--they have what they need." Another pediatrician commented from a social vantage that "all people involved with (the child's) care are in contact—(offering) different viewpoints of the child's day—and everyone is on the same page."

Question 17a: What do you remember about the Early Intervention Module that made it easier for you to serve your patients who are receiving these services?

Community visits: Being out in the community was important for learning about early intervention in the setting in which it takes place. "Going on early intervention visits was helpful—taught me what was possible & what kind if children could benefit." And, "Being familiar with what everything is—having gone to the house with service providers & being able to help parents anticipate what will happen." This also gave the pediatricians insight into role release and the possibility of relief from multiple providers by promoting the "Home model versus medical model—parents can learn to give services themselves."

Familiarity with system: Simply knowing about and being familiar with the system made serving patients and families easier. Among the comments were: "Understanding that it exists and knowing where to refer." And, "Being able to explain how easy things are to access. What to expect in assessment & once the IFSP has been put into practice" makes it easy to help families get services. And, "knowing the framework—who is responsible and what can be provided." One physician commented that she "found that colleagues don't know the details as I do. (Another new pediatrician in her practice)...knows nothing about making referrals."

Question 17b: What do you remember about the Special Education Module that made it easier for you to serve your patients who are receiving these services?

Community visits: Going into the community schools and seeing how Special Education works first hand made this module work well. "Visiting schools and seeing what happens & which kids are served." Having the "chance to talk to teachers in school visits—(made me) more conscious of…(the) value of input from doctors." "Seeing a PPT and IEP—being familiar with them makes it easy."

Knowing the system: Being familiar with the Special Education system made it easier for the physicians to get appropriate help for their patients and families. Knowing the system made it "easy to explain what to expect & how to argue with the school system--either parents for themselves, or the physician on their behalf." Understanding "the importance of advocating prior to PPT so that things are in place as needed." Understanding "mainstreaming concepts—able to ask more direct questions to family and program and look for provision of related services and regular education classes for most kids."

Question #18: In what way has the information you learned about occupational therapy, physical therapy, speech therapy and audiology been useful in your work with patients and families, or in your work in the community?

Helping families: The physicians feel that because they have an understanding of the services of various therapists, they can help their families who have children with disabilities because they can convey to them exactly what to expect from the therapist. "Seeing them in action helps me to explain to families what they might expect."

Patient care: Knowing more about the skills and background of these other professionals helped the physicians in decision making regarding their patients. "Knowing subtle differences between OT and PT so as to know which is beneficial." And, "Knowing more about what each specialty does helps to know how it can be used." And, "Knowing what each of them do so I can utilize them and tell parents what to expect before their initial visit."

Earlier referral: Exposure to the various therapists caused physicians to think about referring earlier than they otherwise might have. "I'm more likely to keep a close eye on things and check with an audiologist or speech therapist sooner that otherwise." And, "It opened my eyes for opportunities for service and testing, particularly in situations where the strengths and capabilities of the child are not obvious (i.e. MR)."

Question #23: As you reflect back on all three years of the curriculum, if you could change just one item, what would it be?

Didactics: Some physicians would like to have fewer didactics and more "hands-on."

Final question: Is there any other information you would like to share with us about the rotation?

Curriculum is very useful: The comments were overwhelmingly positive. "I really feel at an advantage because of what I've learned. The rotation was very helpful." And, "It opened my eyes to mainstream family-centered ways of dealing with kids with disabilities—compared to the segregation that I grew up with (separate classrooms, etc.)" And, "Incredibly useful...it's a good portion of your patient load so you're doing your patients more harm than good if you don't know the information." And, "The biggest advantage is having information that wasn't covered elsewhere. The biggest disadvantage was not being able to go over the information at my own pace, or in a different format (other than lecture)." And, finally, "It's very worthwhile and incredibly useful!"

Post-Residency Physician Survey: Summary of Selected Tables

Table 1: year of graduation
3 physicians from 1998
9 physicians from 1999

Table 2: In Practice or Fellowship/chief residency?
3 physician chief residents
8 physicians in practice
1 physician in fellowship (Neurology)

Table 3: location of practice or fellowship/chief residency
7 physicians in CT
3 physicians in NH
1 physician in VI
1 physician in PA

Table 4: approximate size of practice
Mean: 6,833 patients
Range: 2,000-12,000 (2 unknown)

Table 5: number of pediatricians in practice
Mean: 4.25
Range: 2-6

Tables 6, 7, 8: open-ended questions—see "Themes."

Table 9: number of physicians having patients receiving E.I., and number of patients/physician
Number of physicians with patients receiving EI: 11/12 = 92%
Mean number of patients receiving EI (including outlier): 35
Mean number of patients receiving EI (excluding outlier): 13
Range: 5-200 (including outlier)
Range: 5-36 (excluding outlier)

Table 10: number of physicians having patients receiving Special Education, and number of patients/physician
Number of physicians with patients receiving Special Education: 12/12 = 100%
Mean number of patients receiving Special Education: 26
Range: 1-26

Table 11: number of physicians who have made referrals to Early Intervention or Special Education
Referrals to E. I.: 12/12 = 100%
Referrals to Special Education: 11/12 = 92%

Table 12: number of physicians who have reviewed an IFSP and/or an IEP
Reviewed IFSP: 9/12 = 75%
Reviewed IEP: 10/12 = 83%

Table 13: number of physicians who have attended an IFSP or an IEP
Attended an IFSP or an IEP: 2/12 = 17%

Table 14: number of physicians who have interacted with EI providers or with the school system in other ways, and the method used
Number of physicians who have interacted in other ways: 10/12 = 83%
Method used: Letter & telephone, 4/12 = 33%
Letter alone, 2/12 = 17%
Telephone alone, 4/12 = 33%

Tables 17a, 17b, 18: open-ended questions—see "Themes."

Table 15: number of physicians who have made referrals for additional funding for families, agencies referred to, and physician comfort level at agency referrals
Number of physicians who have made referrals for additional funding: 9/12 = 75%
Agencies referred to by physicians: SSI, 2/12 = 17%
Medicaid, 5/12 = 42%
WIC, 4/12 = 33%
Other, 6/12 = 50%
Multiple referrals = > 100% for total
Number of physicians feeling comfortable referring to these agencies: 10/12 = 83%

Table 16: Number of physicians who sit on boards or committees that serve the welfare of children, and types of committees
Number who sit on boards or committees: 3/12 = 25%
Types of boards or committees: Transport, AAP, Transitions, Parent Guidance Counselor

Table 17: number of physicians who have advocated at a systemic level, and method of advocating at the systemic level
Number who have advocated at a systemic level: 2/12 = 17%
Method of advocating: letter writing, attended legislative hearing, met with legislators, joined coalition.

Tables 18, 19: open-ended questions—see "Themes."

NOTICE

REPRODUCTION BASIS