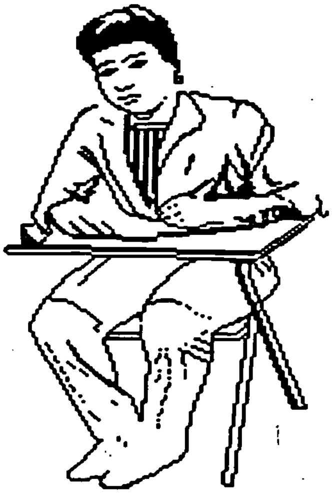
DOCUMENT RESUME

ED 407 771 EC 305 527

TITLE	Early Intervention and Special Education in Connecticut: The Physician's Role.
INSTITUTION	Connecticut Univ. Health Center, Farmington.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	[97]
NOTE	183p.; Appendix A of "Physicians Training Project. Final Report," see EC 305 526.
CONTRACT	H029K20361-94
PUB TYPE	Guides - Classroom - Learner (051)
EDRS PRICE	MF01/PC08 Plus Postage.
DESCRIPTORS	Agency Cooperation; Autoinstructional Aids; Consultation Programs; Cooperative Programs; Curriculum Development; Delivery Systems; *Disabilities; Early Childhood Education; *Early Intervention; Educational Legislation; Educational Philosophy; Family Programs; Graduate Medical Students; Higher Education; Individualized Family Service Plans; Interdisciplinary Approach; *Interprofessional Relationship; *Medical Education; Medical Services; Medical Students; Pediatrics; Physicians; *Special Education; *Teamwork
IDENTIFIERS	Connecticut

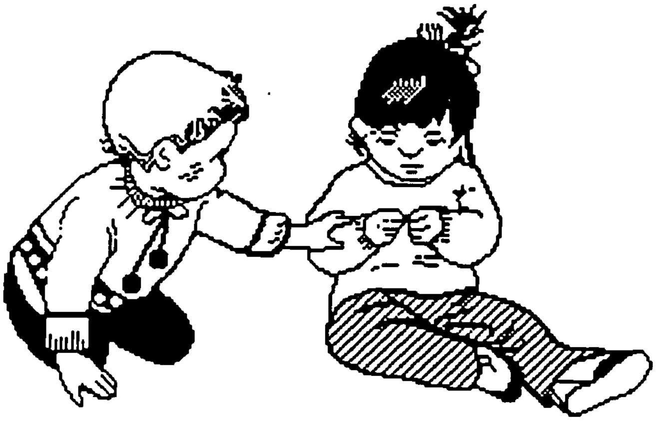
ABSTRACT

This set of nine self-study manuals was developed as part of a project to enhance Connecticut pediatricians, pediatric residents, and medical students' understanding of and involvement with early intervention and the special education system. The training manuals cover the broad areas of philosophy, service delivery models, and collaborative relationships. Emphasized in each of the nine modules is the role of the family as the constant in the child's life and the primary unit for the delivery of services. The manuals cover the following topic areas: (1) family-centered care; (2) educational law; (3) research efficacy; (4) role of other disciplines; (5) curriculum development; (6) natural instructional environments; (7) service coordination; (8) team process; and (9) collaboration consultation. Each manual has four components: a discussion of concepts and values; a family study which provides a case study exercise; a discussion section allowing trainees to apply the concepts learned to the family case study; and the resolution, which suggests a hypothetical resolve which emphasizes physicians defining their roles and responsibilities. (Contains 14 references.) (DB)



Early Intervention and Special Education in Connecticut

The Physician's Role



For Information, Please Contact:
Physicians Training Project
Division of Child and Family Studies
Department of Pediatrics
University of Connecticut Health Center
Suite A200 - Farm Hollow
309 Farmington Avenue
Farmington, Connecticut 06032
(203) 679-4632

All characters in the Family Study section are fictitious. Any resemblance to persons, living or deceased, is unintentional.

The Physicians Training Project is funded as a model demonstration grant from the U.S. Department of Education, Office of Special Education Programs, Division of Personnel Preparation. Grant #H029K203

TABLE OF CONTENTS

PAGE

Family Centered Care

Educational Law

Research Efficacy

Role of Other Disciplines

Curriculum Development

TABLE OF CONTENTS (CONT'D)

PAGE

Natural Instructional Enviroments

Service Coordination

Team Process

Collaboration Consultation

INTRODUCTION

The physician who provides medical care to a child with disabilities plays a key role in the continuing support of the child and his or her family, and recent literature often addresses the role of the pediatrician or family physician in early intervention and special education (Brewer, McPherson & Magrab, 1989; Coury, 1990; Howard, 1982; McInerney, 1984; Shonkoff, Dworkin & Leviton, 1979). 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, in few states are the health system, and the pediatrician or family practitioner, 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 and his or her educational services only increases (Eaton, Coury & Kern, 1989). One reason for this may be physicians' lack of awareness of and knowledge about their role in state systems of early intervention and special education. This is not surprising, considering that neither the preservice nor the inservice training of pediatricians places much emphasis on the care and management of a child with disabilities. However, the emphasis of Part H of the Individuals with Disabilities Education Act (IDEA) on the importance of a multidisciplinary team for early intervention has stimulated interest in improving pediatricians' training (for example, Coury, 1990; Peter, 1992; Schwab, 1991).

The American Academy of Pediatrics (AAP) has been active in developing comprehensive medical education programs to meet the needs of pediatricians in practice. In 1978 an AAP specialty task force released a report which assessed the health needs of children and the educational needs of the pediatricians who treat them. 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 US Department of Education gave the AAP funding to develop an inservice training curriculum that was used with over 5,000 primary care physicians who serve children with disabilities (Powers & Healey, 1982). Since then, however, few programs have had such scope and ambition (Coury, 1990).

Researchers have advocated for many years (Dworkin, Shonkoff, Leviton, 1979; Haggerty, 1974) that pediatricians receive continuing education on the care of children with disabilities. Recent recommendations have focused on educating pediatricians 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. The concept of such a home has been endorsed by the AAP and by the Bureau of Maternal and Child Health (National Center for Networking Community-Based Services, 1989). In order for physicians to provide services based on this model of medical care, however, they first must receive training.

A 1993 survey of practicing Connecticut pediatric/family physicians showed not only a need for additional medical school/residency training on children with disabilities, but also on the early intervention and special education systems from which these children receive services. This survey was conducted by the University of Connecticut Health Center's Division of Child and Family Studies Physicians Training Project.

Training Manuals

This training manual is a response to the Connecticut physicians' request for medical school students to receive additional training on children with disabilities. This manual will provide information to practicing pediatricians, pediatric residents, and medical students regarding their involvement with the early intervention and special education systems, in their capacity as primary physicians for children with disabilities and their families.

The three areas of training will include: 1) philosophy, 2) service delivery models, and 3) collaborative relationships. Figure 1 contains an overview of the content and organization of the training manuals. In the center of the figure stands the family; this reflects the project's central philosophy and its commitment to family-centered care.

All training materials and activities are founded on the beliefs that:

- The physician must see the family as the constant in the child's life, and the primary unit for the delivery of services.

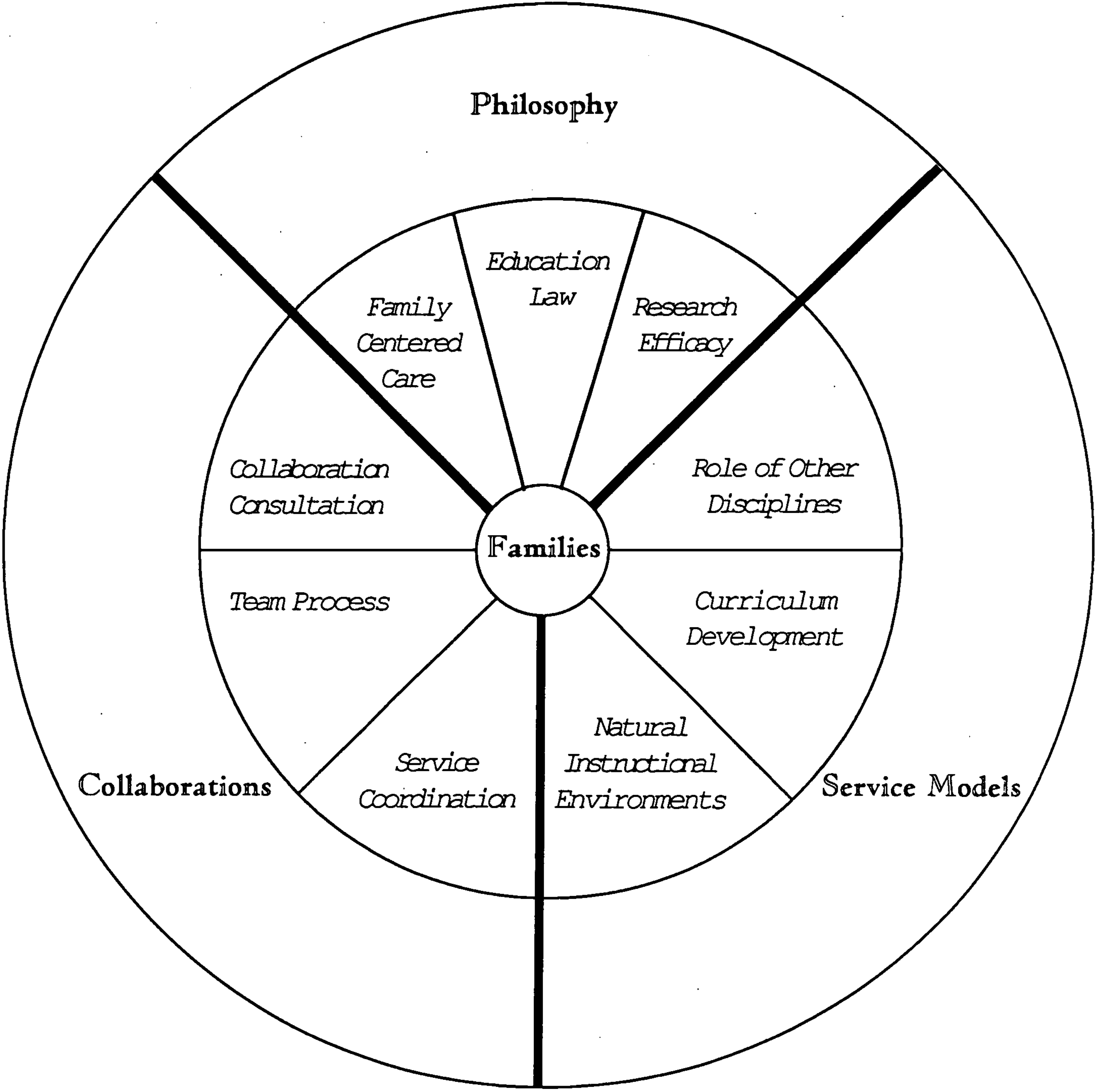


Figure 1. Overview of Material Content and Organization.

- Family-centered, community-based care must be available for all children, regardless of disabilities, illnesses, and cultural backgrounds.
- Intervention models must be designed to accommodate families of various cultures and backgrounds.
- Innovations in family-centered services must be translated into standard community practice.
- Collaboration needs to be ongoing among service providers and between service providers and families.
- A primary goal is the inclusion of children with disabilities in all normal activities and situations wherever and whenever possible.

This training guide consists of eight self-study manuals. Together, they are designed to enhance physicians' understanding of their role in the early intervention and special education systems by exploring related topics. Each manual is similar in layout and has been designed to provide physicians with an opportunity to apply the information they have learned. The manuals are divided into four components. The **first component** discusses <u>concept and values</u>: What is the concept? Why is it important? How does it relate to children with special needs? The **second component**, the <u>family study</u>, gives the general background, both medical and family histories and the challenges this family is facing. The **third component**, the <u>discussion</u>, provides physicians with an opportunity to apply the concepts learned to the family situation described. The **last component**, the <u>resolution</u>, provides a hypothetical resolve which emphasizes physicians defining their roles and responsibilities.

The manuals should be studied in the following order:

1. Family Centered Care
2. Education Law
3. Research Efficacy
4. Role of Other Disciplines
5. Curriculum Development
6. Natural Instructional Environments
7. Service Coordination
8. Team Process
9. Collaborative Consultation

These self-study manuals are part of the training that will be individually designed for each audience: the major thrust of this training is to enable medical students, pediatric residents, and practicing physicians to participate within the early intervention or special education system for children with disabilities and/or chronic illness.

References

Brewer, E., McPherson, M., Magrab, P., & Hutchins, V. (1989). Family-centered, community-based, coordinated care for children with special health care needs. Pediatrics, 83(6), 1055-1060.

Coury, D. (1990). Training physicians for increased involvement with children with special needs. Infants and Young Children, 2(4), 51-57.

Dworkin, P. H., Shonkoff, J. P., Leviton, A., et. al., (1979). Training in developmental pediatrics. American Journal for Disabled Children, 133, 709-712.

Eaton, A. P., Coury, D. L., & Kern, R. A. (1989). The roles of professionals and institutions. In R. E. Stein (Ed.), Caring for children with chronic illness: Issues and strategies New York: Springer.

Haggerty, R. J. (1974). The changing role of the pediatrician in child health care. American Journal for Disabled Children, 127, 545-549.

Howard, J. (1982). The role of the pediatrician with young exceptional children and their families. Exceptional Children, 48, 316-322.

Koop, C. E. (1987). Suregon General's Report: Children with Special Health Care Needs-Campaign '87-Commitment to Family-Centered, Coordinated Care for Children with Special Health Care Needs No. Washington DC: US Department of Health and Human Services.

McInerny, T. (1984). Role of the general physician in coordinating the care of children with chronic illness. Pediatric Clinic of North America, 31, 199-210.

National Center for Networking Community-Based Services. (1989). Establishing a Medical Home for Children Served by Part H of Public Law 99-457. Washington DC: Bureau of Maternal and Child Health and Resources Development and the American Academy of Pediatrics.

Peter, M. I. (1992). Combining continuing medical education and systems change to promote physician involvement. Infants and Young Children, 4(4), 53-62.

Powers, J., & Healy, A. (1982). Inservice training for physicians serving handicapped children. Exceptional Children, 48, 332-336.

Schwab, W. E. (1991). Teaching family centered care to medical students--The University of Wisconsin curriculum. Medical Home Newsletter, 4, 2, 5-8.

Shonkoff, J., Dworkin, P., Leviton, A., et. al., (1979). Primary care approaches to developmental disabilities. Pediatrics, 64, 506-514.

The Task Force on Pediatric Education. (1987). The Future of Pediatric Education. Evanston, IL: American Academy of Pediatrics.

FAMILY CENTERED CARE

The family is the constant in every child's life.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Family Centered Care philosophy.**
- **Apply the nine principles of Family Centered Care.**

Philosophy

Family Centered Care is a philosophy developed by the former Surgeon General, C. Everett Koop, M.D., Sc.D. **It is a philosophy of care which encompasses family centered, community based, coordinated services for children with special health care needs and their families.** A major premise of this approach is that the child is part of a family, and the family has, of course, great impact on the development and well being of the child. A family centered approach to providing services to the child and his or her family thus depends on building and maintaining a relationship based on mutual trust and respect between professionals and the family

The principles of Family Centered Care were further defined and expanded upon in <u>Family Centered Care for Children with Special Health Care Needs</u>, published by the Association for the Care of Children's Health (ACCH) in 1987. In 1990, with input from a large group of families and providers of services to children with complex health care needs, ACCH revised and expanded the original number of principles to the nine which are currently accepted. These nine principles are to develop systems of care that would: 1) assist in the delivery of services to children with special health care needs and 2) support the needs of the family (Shelton, Jeppson, and Johnson, 1987).

In a family centered approach to serving children with health care needs and disabilities, doctors and other professionals no longer play their traditional roles. Thus all health care professionals should review the family centered priciples discussed here to ensure that the services they provide meet the needs of both the child with special needs and the family who is the center of care for that child.

The 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--but the family will always be there, the single and most important source of constant support for their child. It is essential that professionals recognize and respect this central role that the family plays in the care of their child. Ultimately, each family must assume responsibility for their child's care, both daily and for the long term. Professionals must learn to work in partnership with each family, valuing their judgment and respecting their values and vision.

2. **Facilitation of parent/professional collaboration at all levels of health care.**

   Successful care plans must be developed through a meaningful collaboration that reflects each family's strengths and is tailored to each family's needs. The ultimate success of this process depends on the ability of parents and professionals to work in partnership. In a family centered model the family is in charge and the professionals serve as consultants in the child's care.

3. **Sharing of unbiased, complete information with the parents about the child's care on an on-going basis and in an appropriate, supportive manner.**

   A true partnership between parents and professionals requires that parents have access to complete information, written 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.**

   Because each family is unique, the support that each requires reflect their individual values, strengths, coping styles, and visions for the future. Family support therefore means "whatever it takes" for the family to achieve its goals and visions: this philosophy assumes that the family is in the best position to determine exactly what they will need. The needs may include funding, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, 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 these 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, values, culture, and coping style.

6. **Understanding and incorporating the developmental needs of infants, children, and adolescents, and their families into health care systems.**

   In addition to each child's health care needs, a comprehensive health care plan must address other issues as well. Because each child and family has need for socialization, development, and community support, the care plan should allow each parent to fulfill his or her role as parent, and each child to have as normal a life with family and friends as possible.

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.**

   The needs of each child and family will change over time. It is critical, therefore, that service providers be able to respond to these ever-changing needs through 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 child with complex care needs. 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, and 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 exit.

Table 1 provides questions physicians should ask themselves to help ensure they are providing family centered care:

Table 1

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 my decisions?
Collaboration	• Have I met with or contacted all the professionals serving this family? • Have I let the family and professionals know how to contact me?
Information	• Have I been completely honest with the family regarding 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 (particularly, in the family's primary language)?
Policies and Programs	• Have I informed the family of an agency that can help them deal with all 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)?
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 allow the family and child to meet their normal needs?
Support	• Have I encouraged the family to seek out the support of other families and agencies?
Healthcare	• Have I clearly let the family know of the services they qualify for? • 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?
Families	• Have I considered the family's culture and values when prescribing my treatment?

FAMILY STUDY

JP is about to be discharged from the newborn intensive care nursery after a twenty-week hospitalization following his premature birth. He developed seizures at 72 hours, which were controlled by medication, and required ventilation for three weeks. He also had difficulty feeding by mouth. His mother, Susan, is a seventeen-year-old single parent in good health. She works an average of 30 - 40 hours a week, with no insurance benefits, as a secretary for a temporary employment agency. Susan 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.

Susan 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, Susan does have a few close friends who have visited JP with her at the hospital. Susan will need support in her roles as primary provider of JP's care and as primary decisionmaker for his health care needs.

Susan had some difficulty keeping her schedule of hospital visits, although when she did visit JP she often sat and rocked him for hours. Her missed visits made it difficult for the hospital staff to adequately train Susan in JP's care; however, toward the end of JP's hospitalization, Susan 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.

Susan lives in a one-bedroom apartment across town from the hospital. She does not have a telephone, so that maintaining contact with the hospital when she could not visit was difficult.

JP has a number of continuing medical concerns, including a need for seizure medication, and assistance during feedings. Because his muscle tone is poor, he is unable to suck for long periods. His calorie intake must therefore be monitored to make sure he gains enough weight.

Susan 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 questions Susan's abilities 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.

DISCUSSION

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

What are the family's needs/concerns?

Who should explore the issues affecting Susan'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 are the potential barriers to implementing the discharge plan?

Who addresses the barriers identified in the discharge meeting?

What are the providers' (professionals) issues?

What do you want included in the discharge plan for JP?

RESOLVE

Using a family centered model, the following people began discharge planning for JP and Susan after the sixth week of JP's hospitalization, when his health stabilized:

Susan
Primary NICU Physician
Primary Nurse
Discharge Planner (Nursing)
Social Worker (Hospital Based)
Visiting Nurse (Community Based)
Community Physician

The discharge planning included three full team meetings: at 8 weeks, 16 weeks, and just prior to discharge. Susan 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. Susan also met with the social worker on four other occasions, during visits to the hospital. The visiting nurse made one visit to Susan's home before discharge and made an assessment of JP's home care needs.

In these meetings the team explored the strengths and needs of the family. Susan was strongly determined to care for JP at home, and managed to get time off from work to visit JP and participate in the discharge planning. During the two days and one night she spent at the hospital prior to discharge, she learned how to care for JP, including how to operate all his medical equipment. Despite limitations in transportation, she did manage to visit JP. She is very nurturing towards him, spending hours in the hospital just rocking and hugging her baby. She has a few friends who provide her with some emotional support. Susan has managed to keep her job despite the stress and trauma of JP's hospitalization, and is struggling to meet both of their needs.

During the discharge planning process, Susan identified several concerns, including a lack of insurance benefits, and concern over how JP's hospitalization and continuing care needs will be paid for. She will need to find child care for JP, and expects that this will be difficult because of his medical and developmental needs. She also has neither a car of her own nor access to one, for getting to appointments; furthermore, she is concerned about taking too much time off from work. She is also worried about the possibility that JP will have long-term care needs and will be disabled. She has no one to support her and assist her in understanding these issues.

The team wrote the discharge plan at their last meeting, and team members carefully explained the plan to Susan. A referral for early intervention was discussed with Susan and she said she would think about it. Her copy of this document included, in addition to telephone numbers and appointments, the following:

- What medical equipment to obtain from a home-health supply vendor
- Proper dosage and administration of medication for seizures
- Referral to early intervention services for developmental follow-up and physical therapy

- Referrals for follow-up in the following specialties: ophthalmology, neurology, pulmonology, audiology, and developmental follow-up clinic
- Referral for eight hours of home nursing per day

In addition to JP's medical/developmental needs, Susan's other concerns were addressed through the discharge plan.

Susan's need for a telephone. The hospital social worker secured a donation from a local charitable foundation to have a phone installed; Susan understands that ongoing bills will be her responsibility.

Health care financing. Susan 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 will pay for transportation to medical appointments.

Multiple care providers and appointments. The visiting nurse agreed to act as a service coordinator, and will assist Susan in coordinating appointments on the same day.

Support needs for Susan. Prior to JP's discharge, Susan 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 will help Susan find permanent work.

Child care needs for JP. JP will receive eight hours a day of home nursing while Susan is working; this coverage will continue as long as JP needs skilled care. Should his condition improve, Susan will again need to find child care. The Visiting Nurse Association will assist her in training someone, but Susan is 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, Susan and JP can have a satisfying life together.

DISCUSSION - ANSWERS

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

- Susan loves JP
- Susan's strong determination to provide care for JP at home
- Susan took time off from work to participate in the planning process for JP's discharge
- Susan visited JP despite transportation difficulty
- Susan has some friends for emotional support
- Susan has kept her job throughout the stress and trauma of JP's hospitalization

What are the family's needs/concerns?

- Insurance Benefits
- Child care
- Transportation
- Help coordinating JP's doctors' appointments
- Support for Susan to help her understand JP's needs
- Employment counseling for Susan

Who should explore the issues affecting Susan'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?

- Susan, JP's pediatrician, primary care nurse, and social worker (discharge planning team) should be involved in identifying the issues affecting Susan's ability to visit JP in the hospital and participate in his care
- 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 are the potential barriers to implementing the discharge plan?

- Susan's need for a telephone
- Health care financing
- Transportation
- Susan's ability to get JP to multiple appointments without losing her job
- Susan's support needs
- Child care

Who addresses the barriers identified in the discharge meeting?

- The entire discharge-planning team should address these issues

What are the providers' (professionals) issues?

- Making sure JP has his medical needs met at home, including medical equipment, medicine, therapy and appropriate medical and early intervention referrals

What do you want included in the discharge plan for JP?

- Medical equipment from a home health supply vendor
- Medication for seizures
- Referral to early intervention and physical therapy
- Referrals for medical follow-up appointments

REFERENCES

Koop, C.E. (1987). Surgeon General's Report: Children with Special Health Care Needs - Campaign '87 - Commitment to Family-Centered, Coordinated Care for Children with Special Health Care Needs. Washington, DC: US Department of Health and Human Services.

Shelton, T., Jeppson, E., & Johnson, B. (1987). Family-centered care for children with special health care needs (2nd ed.). Washington, DC: The Association for the Care of Children's Health.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Family Centered Care Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

EDUCATION LAW

The Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) address many facets of the child's educational and health care needs.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Individuals with Disabilities Education Act (IDEA) and apply concepts of the law to children with disabilities.**
- **Describe Part H of IDEA (early intervention) and list the services available for eligible infants and toddlers.**
- **Describe the Americans with Disabilities Act (ADA) and apply concepts of the law to children with disabilities.**

As the primary physician treating children with disabilities, it is important for you to become familiar with the laws affecting the education of these children. These laws have many components and specific provisions; we describe below two of the most important laws affecting children with disabilities, and the key provisions of those laws.

Individuals With Disabilities Education Act

The Beginning: The Education for All Handicapped Children Act

In 1975, The Education for All Handicapped Children Act (P.L. 94-142) became law; it guaranteed children with disabilities the right to a free and appropriate public education. This legislation was the culmination of many years of court decisions and legislation expanding access to education for children with disabilities. The Education for All Handicapped Children Act mandated a free and appropriate public education for children with disabilities **ages 5-21** regardless of the nature or severity of the handicap.

The Education for All Handicapped Children Act defines **special education** as "specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child" in accordance with an **Individualized Education Plan (IEP).** The child may receive this instruction in the classroom, in the home, in hospitals and institutions, and in other settings, such as community early childhood programs.

The Amendments

In 1986, Congress amended P.L. 94-142 to P.L. 99-457, and added a number of specific components significant for **children under age five**. **Part B** of this amendment stipulates that:

- services for children who are age 3-5 and who are determined to be eligible for special education are **mandated** under the provisions of a free and appropriate public education
- services are to be provided to each eligible child or adolescent regardless of the severity of the individual's disability

Part H, Early Intervention Services For Infants And Toddlers created incentives for states to develop an early intervention entitlement program for children **from birth through age three**. This part of the law describes a comprehensive statewide system of interagency, multidisciplinary services that should be available to eligible children. Each state must determine its own eligibility criteria. Many states, such as Connecticut, now provide very young children with such early intervention services, under a state mandate which complies with the federal Part H requirements. Many important services specified by Part H are available to families of eligible infants and toddlers:

- Each eligible infant or toddler and his or her family shall receive a multidisciplinary assessment and an **Individualized Family Service Plan (IFSP)** which should include:
    a) the present level of the child's development
    b) a statement of the family's priorities, resources, and concerns
    c) a statement of expected major outcomes for the child
    d) a statement of necessary services for the child
    e) projected dates of these services, and their duration

f) the steps for supporting the child's transition to the mandated school program

g) the name of a service coordinator

- Each state is required to establish a **State Interagency Coordinating Council** whose role is to advise and assist the lead agency for early intervention. The membership of the state **ICC** will include at least:

  a) three parents of infants or toddlers with disabilities

  b) one representative from the state legislature

  c) three public or private providers of early intervention services

  d) one person involved in professional preparation

  e) other representatives from each of the appropriate agencies involved in the provision of or payment for early intervention services

  f) others appointed by the Governor

In 1991, these amendments to P.L. 94-142 were passed; the law became P.L. 101-476 and was renamed the **Individuals with Disabilities Education Act (IDEA).** The name change reflects a shift in terminology from "handicaps" to "disabilities".

Under **Part A General Provisions**, this law stipulates that:

- A free, appropriate public education is assured for all eligible children with disabilities

- The eligible disabilities include mental retardation, hearing impairments, speech and language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, and specific learning disabilities

- **Related services** (see Appendix A) be provided, including:

  > transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education: these include speech pathology and audiology, psychological services, physical and occupational therapy, recreation (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services (including rehabilitative counseling), and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training.

- Transition services for secondary-age students

The Major Components of IDEA are:

The Zero Reject Principle: A free, appropriate public education is guaranteed for all children ages 3-21 regardless of the severity of the individual's disability. Children under three may be provided with services if state law, regulation, or judicial ruling mandate them.

Nondiscriminatory Assessment: A multidisciplinary team must conduct the evaluation in the child's primary language or mode of communication, using observations and non-biased, validated instruments. The student must be assessed in all areas related to the suspected disability. The assessment should allow the child to display his or her abilities and strengths, as well as disabilities.

Individualized Education Plan (IEP): An appropriate Individualized Education Plan must be written for each child. This document should be developed in a Planning and Placement Team (PPT) meeting composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others invited by the parents or the school. The IEP will contain a statement of the child's current level of performance, long term goals and short term objectives, specific educational services the child will need, the date for beginning services and the anticipated duration of the services, the extent of the child's participation in the regular education program, and how to determine whether the goals and objectives for the child are being met.

Least Restrictive Environment (LRE): To the maximum extent possible, schools must educate children who have disabilities with their peers who do not have disabilities:

- Special classes, separate schooling, or otherwise removing a student with disabilities from regular education should occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily even with the use of supplementary aids and services.
- Schools must provide a spectrum of placement options (regular classes, regular classes with minimal support, regular classes with one-to-one assistance, and so on) and supplementary services (adaptive physical education, speech and language, and so on.)
- Schools must provide education as close to the student's home as possible, and allow a student to participate in extracurricular and nonacademic activities to the extent appropriate.
- If a child with disabilities, is removed from a regular education classroom, the school must work to return that child to the regular classroom as soon as possible.

Due Process and Parent Participation: School districts must establish and follow specific procedures in order to protect the rights of children and their families. These procedures should specify that:

- Parents may examine all records pertaining to their child.
- Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.
- Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. They must be informed of the Planning and Placement Team (PPT) conference and encouraged

to participate. Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.

- Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement.
- Parents have a right to an impartial due-process hearing conducted by a hearing officer, and/or mediation if they are in disagreement with the school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the school district.
- Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known, or who are not available.

In addition to the above provisions these amendments include an emphasis on meeting the needs of traditionally under-represented populations (for example, minorities or low-income families). The amendments also expand the definition of special education to include a variety of settings for the delivery of services (for example, a work place or community-based program). States must also insure that **assistive technology devices** and/or **assistive technology services** are made available to a child with a disability if they are required as a part of the child's program. Thus, a child's program may include special education, related services, and/or supplementary aids and services. The legislation states, further, that the related-services list is not exhaustive and may include other developmental, corrective or supportive services, if they are required to assist a child with a disability to benefit from education.

Americans With Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) signed into law by President George Bush on July 26, 1990, is a wide-ranging civil rights law that prohibits discrimination against people with disabilities. The protections it offers are similar to those given to women, minorities, and others subsequent to the Civil Rights Act of 1964. ADA protects an estimated 43 million Americans with physical or mental impairments that substantially limit their activities, such as working, walking, talking, seeing, hearing, or caring for themselves. People who have such impairments, as well as those who are perceived to have impairments, are also protected.

ADA bars discrimination in employment and requires most employers to make **reasonable accommodations** for employees with disabilities. It also prohibits discrimination in commercial facilities, with regard to public accessibility, as well as discrimination in any activity or service operated or funded by state or local government. This may include daycare centers and others programs which serve children <u>without</u> disabilities.

FAMILY STUDY

Trevor is a nine year old boy who lives with his mother, Sandy, and his father, John. Trevor has two sisters; Lisa, who is six years old, and Ann, who is four. Sandy delivered Trevor 12 weeks prematurely by emergency Cesarean Section. Trevor's birth weight was low, and he was hospitalized for four months because of repeated respiratory distress. Sandy and John visited their son regularly in the hospital and were involved in his hospital care.

Trevor was discharged from the hospital with respiratory problems and required frequent feedings and medications. His parents cared for him at home with little support. Trevor has developmental delays, as documented by a multidisciplinary evaluation requested by his parents shortly after he came home from the hospital at six months of age. Trevor began receiving early intervention services at fifteen months of age. This is Trevor's condition:

- Trevor has cerebral palsy; he is, however, ambulatory.
- He has a marginal airway.
- He currently wears prescriptive lenses and requires preferential seating in school.
- Trevor has repeated bouts of respiratory infections for which he often receives antibiotics.
- Trevor has learning disabilities.
- He has attention problems which require medication.

Presently, Trevor is in a "self-contained" classroom (for students with learning disabilities) at a grade level (4) appropriate for his age. This is the first year that Trevor has been in the self-contained classroom. The school staff believed that this was the most appropriate place for him to be for several reasons, which they clearly communicated to Trevor's family. The reasons for his placement included:

1. Trevor often required that instructions about assignments be repeated.
2. Trevor's behavior in the mainstream or "regular ed" (for non-disabled peers) classroom was often disruptive, and the teacher had a difficult time getting him and the rest of the class back on task.
3. Class sizes were increasing, and the teacher would not be able to give Trevor the more "personalized" instruction he might need.
4. The school staff judged that Trevor's learning disability and his physical disability dictated a more "restrictive" educational setting.

His parents initially agreed to place Trevor in a self-contained program, and this was implemented in his IEP. His mother now feels that this program is not in Trevor's best interest, and has requested that Trevor be placed in a regular-education classroom with individualized support services. She is upset that Trevor has to attend a different school than the other children in the neighborhood, since the self-contained program for his grade level is offered in only one school in the city. Also, he is not attending the same school as his sister Lisa, which makes childcare arrangements even more difficult to manage.

Trevor's parents requested a Planning and Placement Team (PPT) meeting because they were displeased with the school's response to their concerns. At his parent's request, Trevor's neurologist wrote a letter supporting Trevor's placement in a "regular ed" setting with modifications. His mother believes that Trevor's behavior has worsened since he has been in the self-contained class, and Trevor's pediatrician is concerned that he may be acting out his anger about being unhappy at school.

To act as an advocate at the PPT, Trevor's parents brought along a distant cousin of Sandy's, a special education teacher who had been involved in discussions about Trevor's placement in the past. The PPT lasted three hours, but the participants could not reach an agreement. Trevor's parents then filed the appropriate forms with the Department of Education to begin due process to resolve this dispute. They see his educational needs as:

- Modifications to the curriculum and/or classroom day in order to assist him in learning
- Trevor being allowed to have appropriate interaction with his peers, in order to establish positive relationships
- An appropriate evaluation to assess Trevor's current educational needs

DISCUSSION

As Trevor's primary physician, evaluate the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

If, according to the IDEA, Trevor should participate in a regular education program, what part or parts of the IDEA specifically address Trevor's educational needs?

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

If Trevor were two years old, how might this process be different under IDEA Part H?

RESOLVE

Sandy and John filed for a due process hearing for their son, Trevor, with the local school district. As the law states, the State Department of Education must schedule the hearing and render a decision within 45 days of the initial request for the hearing. Sandy and John thought that up to this point they had a working relationship with Trevor's school team; after discussing the issue, they decided to ask the school district officials if they would instead be interested in mediation. The law (P. L. 101-476) does allow for mediation, which is defined as an informal process for resolving disagreements about a student's special education evaluation, program, or placement. In order to obtain mediation, both the parent or guardian and the school district must send written requests to the State Board of Education. The School District agreed to try mediation; the State Board of Education then scheduled a mediation date and appointed a state mediator to help work out a solution acceptable to both parties. The family understood that if mediation did not work, their initial request for a due process hearing would still be valid.

Trevor's parents decided to ask his neurologist, who prescribes and monitors Trevor's medication, to attend the mediation; they also asked Trevor's primary pediatrician to attend. Both physicians agreed to come because they thought it was important to establish with the school a mechanism for ongoing communication about and evaluation of Trevor's progress. Both physicians strongly believed that Trevor should be placed back in regular fourth grade in his neighborhood school, with the classmates he had been with since first grade. The neurologist believed that knowing more about a typical day in regular fourth grade, and the expectations for Trevor within that day, might influence his prescription and timing of Trevor's medication. The neurologist also thought it was important for Trevor to have a behavior management plan in conjunction with his medication. The pediatrician believed he had good rapport with Trevor and his family, and a sense for how Trevor reacted to certain stresses and conditions. He noted that Trevor wanted to express how stigmatized and angry he felt at being placed in the special education fourth grade class, instead of in regular fourth grade with his friends; the pediatrician thus recommended that Trevor speak on his own behalf at mediation, and said that he would help facilitate the process for Trevor. He also said he would be willing to work with Trevor, the school psychologist, Trevor's family, and other team members to develop a behavior plan that was consistent for home and school. Trevor's parents agreed that these were important issues to raise at mediation, and thought that both physicians not only supported their concerns but wanted to work collaboratively with the school district. His parents further agreed that it was important to let Trevor speak at the mediation, as it was his future at stake.

Trevor's parents also asked Trevor's third-grade teacher to attend the mediation. She had told Trevor's parents during the PPT that she would have recommended regular fourth grade if support services could be worked out. She believed Trevor did not have ongoing, consistent supports in third grade, thus making it difficult for her to manage his inclusion in that class. The family wanted to stress to the school staff that when Trevor had previously been placed in regular education, he did not have supplementary supports, a curriculum plan, and a behavior management plan.

The family asked the advocate to attend as well. Since their last PPT meeting, the advocate had told Trevor's parents of a ruling in US District Court for the district of New Jersey; she said she would bring copies of the summary of the opinion for everyone at the mediation. In brief, the court defined inclusion as follows:

> "When a child with a disability is placed as a full member of a regular class with the provision of supplementary aids and services this is known as supported inclusive education."

The court also noted that:

> "An inclusive education program, where a child with a disability becomes a member of a regular class, does not imply that all special service delivery must occur within the regular class. For instance, resource room support, or other special services, may be delivered on a pull-out basis within the regular class, or a combination of the two, depending upon the needs of the child and the class as determined by the teachers and team involved."

The court ruled that any Individual Education Plans recommending self-contained special education classes with no meaningful opportunities for integrating the child with non-handicapped children violated IDEA. The school district also violated IDEA when it placed the student in a regular class for a portion of the day without supplementary support, without a curriculum plan, and without a behavior management plan. Trevor's parents were elated: this is exactly what they had been trying to explain to school district officials in terms of Trevor's initial placement in regular education.

Trevor's parents were comfortable with the group of professionals they had chosen to go with them to mediation. They believed that the group would support their goal of an inclusive fourth-grade placement for Trevor, and offer ongoing support to school district officials if they agreed to place Trevor back in regular education. Trevor's parents also thought it was important that the mediator and school district officials listen to Trevor voice his concerns. The family went to mediation with a positive attitude: they believed that it was important to try to negotiate and talk things through. If that didn't work, however, they were prepared to pursue this issue at the impartial hearing that is their right under the law.

DISCUSSION - ANSWERS

As Trevor's primary physician, evaluate the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

- Collaborate with members of the PPT and other health care providers regarding Trevor's medical needs and the impact of these needs on his educational programming
- Clearly state Trevor's needs for medical intervention within the school, such as dispensing of medications
- Ascertain whether a comprehensive evaluation of Trevor's educational needs has been completed
- Determine the need for any assistive technology services or devices

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

- Yes

If, according to the IDEA, Trevor should participate in a regular education program, so, what part or parts of the IDEA specifically address Trevor's educational needs?

- Development of an IEP defining eligibility needs for special education programming and related services (Part A)
- Part B (for ages 3-21)
- Least Restrictive Environment component

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

- Parents feel that the self contained classroom is not benefitting Trevor because:

  a) It is not in the neighborhood school
  b) It excludes Trevor from the mainstream or regular classroom
  c) They see Trevor's behavioral difficulties increasing
  d) It complicates their childcare arrangements

- Less restrictive alternatives within the neighborhood school or the regular education classroom were not tried prior to placing Trevor in the self contained program

- Trevor may be in need of a comprehensive evaluation

- His parents do not feel supported by the school staff

- Trevor needs to have contact with non-disabled peers

- Parents appropriately requested a PPT meeting to review Trevor's program and sought support from their pediatrician, their neurologist, and an advocate

If Trevor were two years old, how might this process be different under IDEA Part H?

- Under Part H an IFSP would be written rather than an IEP, and would include a statement of the family's strengths and needs, the name of a service coordinator, and possibly steps for moving Trevor into the public schools at age three

APPENDIX A

Services Available for Eligible Infants and Toddlers under Part H of IDEA

- Audiology
- Case management services (service coordination)
- Family training, counseling and home visits
- Health services
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Social work services
- Special instructional services detailed to the child's needs
- Speech/language pathology
- Transportation
- Vision services
- Assistive technology and devices
- Parent-to-parent services

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Education Law ____________ Date ____________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

RESEARCH EFFICACY

The efficacy of a program is not always measured against quantitative norms.

Objectives:

Upon completion of this manual, you will be able to:

- **Define efficacy.**
- **Identify the variables which contribute to the efficacy of a program.**
- **Describe how efficacy might be measured in working with children who are at risk or those with disabilities.**

Research Efficacy

Efficacy is the positive effect that a program, strategy, or procedure has on the group at which it was aimed. In early intervention we are concerned with the efficacy of programs designed for children who may be at risk for developing problems due to environmental factors (Bronfenbrenner, 1975; Horowitz & Paden, 1973; Ramey, MacPhee & Yeates, 1984; Ramey, Yeates, & Short, 1984) as well as those at risk due to biological factors (Bricker, Bailey & Bruder, 1984; Dunst, 1985; Shonkoff & Hauser-Cram, 1987). Despite methodological limitations, the research done thus far support the effectiveness of early intervention programs with both groups of infants. Unfortunately, the accumulated data does not reveal which service delivery variables may be best suited for different types of family, children, and particular needs.

Principles of Efficacy

In early intervention and special education, efficacy does not necessarily mean a significant change in a child's Intelligence Quotient (IQ) scores. Rather, the efficacy of a program might be apparent in a number of other, possibly more important, areas, such as social behavior, adjustment to the family, or adaptive skills. A program also might produce gains in one area (for example, changes in the child) while not producing gains in other areas (for example, changes in the parents).

The program still could be considered effective, however, in these specific domains.

Demonstrating abilities in the "normal" range isn't necessarily a good measure for the progress of a child with disabilities; normal goals are in most cases beyond the reach of the child, or of current expertise and technology. Families of children with disabilities need to understand, therefore, that "normal" developmental goals may be inappropriate or unrealistic for their child. It is also important that the family have information regarding appropriate goals and the role that early intervention might play in attaining those goals. For example, a child with low muscle tone may not be able to roll over at the normal developmental age, but, with physical therapy provided through an early intervention program, the child may gain muscle tone and learn to roll over at a later stage of development.

Parents also should be aware that children with disabilities can develop **secondary handicapping conditions**, complications that result from the primary handicapping condition. For example, a child might suffer from low weight gain due to oral-motor difficulties, or muscle contractures or atrophy due to lack of movement. Early intervention services may prevent these additional complications from occurring.

According to the House Report (99-860)(1986) which accompanies the Individuals with Disabilities Education Act (P.L. 99-457), early intervention and early childhood special education programs can:

- enhance intelligence in some children;

- produce substantial gains in physical development, cognitive development, language and speech development, psychosocial development, and self help skills;
- prevent the development of secondary handicapping conditions;
- reduce family stress;
- reduce societal dependency and institutionalization;
- reduce the need for placement in special education programs once children reach school age; and
- save money for society and our nation's schools.

Future research may identify what specific variables contribute to efficacy in early intervention programs. Such variables may include child and family characteristics, program features, and goals and objectives (Guralnick, 1989).

Certainly, effective early intervention benefits the child not only directly but indirectly. By allowing parents to be parents, by encouraging them to nurture their child rather than take on a host of professional responsibilities (such as, occupational therapy and physical therapy), the parent-child bond can deepen. This bond is critical to the child's developmental process. An effective early intervention program may also help parents locate a parent-to-parent support network, through which they can explore their expectations for their child and her program.

FAMILY STUDY

Scotty is twenty-four months old and living at home with his mother, father, and eight month-old sister. His father works full-time and mother part-time. Scotty was born eight weeks premature and was hospitalized with a variety of problems for the first three months of his life. With the parents' permission, the discharge planning team made an early intervention referral on Scotty's discharge from the hospital, at age three months.

At twenty-four months of age, Scotty has many disabilities:

- Scotty has low muscle tone and does not walk or crawl
- He has feeding difficulties and problems gaining weight
- Scotty has vision problems
- Scotty has breathing problems which require frequent hospitalizations
- Scotty does not talk
- He has trouble sleeping through the night

Scotty has been receiving early intervention services both at his daycare and at the children's hospital. Currently, he has physical therapy three times a week, speech therapy two times a week, and occupational therapy two times per week, as well as visits from his early intervention teacher every other week. Scotty's schedule is as follows:

- Monday: daycare - 4 hours
  occupational therapy at daycare
- Tuesday: daycare - 4 hours

  - physical therapy at the children's hospital
  - speech therapy at the children's hospital

- Wednesday:
  - daycare - 4 hours
  - occupational therapy at daycare
  - early intervention teacher every other week
- Thursday:
  - daycare - 4 hours
  - physical therapy at the children's hospital
  - speech therapy at the children's hospital
- Friday:
  - daycare - 4 hours
  - occupational therapy at daycare

While at the doctor's office to have an ear infection of Scotty's treated, his mother and father begin discussing Scotty's lack of progress. Scotty's mother and father are tired and discouraged. After twenty months of early intervention therapy services, they perceive Scotty to be showing little improvement. He still doesn't crawl or talk, and already his little sister is beginning to make noises and talk. With Scotty not sleeping through the night, his sister needing their attention, and the demands of life in general, the parents don't see the point of continuing these therapies: they take up a great deal of time, and Scotty's parents don't see the results they thought they would.

DISCUSSION

As Scotty's pediatrician, how will you address the following?

What are the family's concerns?

What variables should you look at when defining the efficacy of Scotty's program?

How would you address the family's concerns and what would you recommend to them?

Scotty's family is measuring the effectiveness of this therapy against his sister's progress. How would you help develop a program for Scotty in which the parents can better see his progress?

How could you help the family to understand what expectations are realistic for Scotty?

RESOLVE

Clearly, Scotty's parents are questioning the effectiveness of the early intervention programming he is receiving. Despite the services of the physical therapist, occupational therapist, speech therapist and early intervention teacher, the parents feel that Scotty is making no progress, particularly in crawling and talking. The physician is aware of the stress and disappointment Scotty's parents are suffering; she asks them what their expectations are, and why they think that Scotty is not making progress.

Scotty's parents reply that after twenty months of intervention, they expected him to be crawling and to have a few basic words such as mommy, daddy, and juice or milk. They are also concerned and confused about why these goals haven't been met. The physician suspects that Scotty's parents have not been given clear expectations by the early intervention service providers, and that the services may not be well coordinated; she also wonders if the parents have enough emotional support.

The physician suggests that Scotty's parents request a meeting with the early intervention team, and says that she also will attend. The meeting is thus scheduled with the occupational therapist, physical therapist, speech therapist, daycare teacher, physician, and Scotty's parents. Each of the service providers discusses how he or she sees Scotty's progress, and redefines the goals toward which he or she is now working. The parents realize that their expectations had been too high and that they had not recognized the progress Scotty had made since early intervention began. The physician observed that Scotty's parents were having a hard time emotionally, and asked about resources to provide Scotty's parents with more support. The physical therapist told them about the parent-to-parent support network and said he would call the parents with the name and phone number of a person whom they could contact.

DISCUSSION - ANSWERS

As Scotty's pediatrician, how will you address the following?

What are the family's concerns?

- Scotty's progress is not what the family expected
- Early Intervention is not effective
- Scotty's parents feel stressed and discouraged

What variables should you look at when defining the efficacy of Scotty's program?

- Improvements in Scotty's verbal skills and his physical development (muscle tone)
- The adjustment of the family
- Changes in Scotty
- Weight gain
- Effectiveness of early intervention program in terms of the gains Scotty has made and in preventing secondary handicapping conditions from developing
- Communication among early intervention team and between service providers and the family

How would you address the family's concerns and what would you recommend to them?

- Have parents contact service coordinator to convene early intervention team meeting
- Revise the Individual Family Service Plan
- Explore additional support services for the family

Scotty's family is measuring the effectiveness of this therapy against his sister's progress. How would you help develop a program for Scotty in which the parents can better see his progress?

- Look at individual growth instead of developmental milestones
- Define where Scotty is now and what the next step is in his progression of development
- Focus on skills he has acquired (for example, social development as well as physical development)

How could you help the family to understand what expectations are realistic for Scotty?

- Look at individual growth instead of developmental milestones
- Define where Scotty is now and what the next step is in his progression of development
- Focus on skills he has acquired (for example, social development as well as physical development)

REFERENCES

Bricker, D., Bailey, E., & Bruder, M. (1984). The efficacy of early intervention and the handicapped infant: A wise or wasted resource. In M. Wolraich & D. Routh (Eds.), Advances in developmental and behavioral pediatrics (pp. 373-423). Greenwich, CT: JAI Press.

Bronfenbrenner, U. (1975). Is early intervention effective? In M. Guttentag & E. L. Struening (Eds.), Handbook of evaluation research (pp. 519-603). Beverly Hills: Sage.

Dunst, C. (1985). Rethinking early intervention. Analysis and Intervention in Developmental Disabilities, 5, 165-201.

Guralnick, M. (1989). Recent developments in early intervention efficacy research: Implications for family involvement in P.L. 99-457. Topics in Early Childhood Special Education, 9(3), 1-17.

Horowitz, F., & Paden, L. (1973). The effectiveness of environmental intervention programs. In B. Caldwell & H. Ricciuti (Eds.), Review of child development research Chicago, IL: University of Chicago Press.

Individuals with Disabilities Education Act (1991). P.L. 102-119 (20 U.S.C.) Sections 1400-1485.

Ramey, C., Yeates, K., & Short, E. (1984). The plasticity of intellectual development: Insights from preventive intervention. Child Development, 55, 1913-1925.

Ramey, C. T., MacPhee, D., & Yeates, K. O. (1984). Preventing developmental retardation: A general systems model. In L. A. Bond & J. M. Joffe (Eds.), Facilitating infant and early childhood development (pp. 343-401). Hanover, NH: University Press of New England.

Shonkoff, J. P., & Hauser-Cram, P. (1987). Early intervention for disabled infants and their families - A quantitative analysis. Pediatrics, 80, 650-658.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Research Efficacy Date ____________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

ROLE OF OTHER DISCIPLINES

All disciplines have expertise which are equally important in developing a service plan for a child.

Objectives:

Upon completion of this manual, you will be able to:

- **Define special education and related services.**
- **Identify the roles of other professionals who may provide related services to an infant or child recieving special education.**
- **Describe and apply the components of a successful integrated therapy model.**

Because all children have different cognitive, physical, and psychological characteristics, they all require educational programs designed to meet their unique needs. Children ages 3 - 21 who have disabilities are entitled to special education and related services to meet their individual needs through P.L. 101-476, The Individuals with Disabilities Education Act (IDEA). Part H of IDEA also provides early intervention services for eligible infants and toddlers and their families.

Special Education and Related Services

Designing intervention programs to meet the educational needs of children with disabilities is a complex process; no one person has the skills, or knowledge adequate to do this. Rather, many professionals (for example, special education teacher, speech therapist, and physician) and the family must work together as a team to provide information, make decisions, and perform all the functions associated with delivering special education and related services. In order to avoid confusion and the fragmentation of services, it is essential that this team of people work collaboratively to plan, coordinate, and implement the services needed for each child. They will need to communicate with one another, share their expertise and skills, make joint decisions, and most important, coordinate their service delivery efforts.

Special education and related services are defined in P.L. 101-476 as:

Special Education: Specifically designed instruction that is developed by a team to address the individual educational needs of the child. It is provided through a child's Individual Family Service Plan (IFSP) or Individual Education Plan (IEP). The Special Education Teacher provides the environment, activities, equipment, and methods/interventions to facilitate a child's development/education.

Related Services: Include transportation and developmental, corrective, and other supportive services needed to assist a child with a disability and his/her family to benefit from special education.

Thus, each child may receive, in addition to a program of specialized instruction (special education), any one or a combination of the following related services, as stated on the IFSP or IEP: audiology or hearing services, medical services, occupational therapy, physical therapy, psychological services, school health services, speech therapy, social work, and vision services. Each person providing special education or one of these related services to a child with disabilities has a role specifically related to their discipline.

Roles of the Professionals

Each of the related service professionals listed above has training and expertise in his or her discipline, and each, acting within that discipline, contributes to or provides services to the education of children with disabilities. Their roles are described as follows:

Aide:	A person assigned to work directly with a child or in the same classroom to help meet educational needs, implement goals, and provide physical assistance to the child (for example, an aide might help implement a child's toilet training program).
Audiologist:	Evaluates hearing, provides rehabilitation when appropriate, and assists the team in understanding the nature of a child's hearing loss and how it may affect the child's development. An audiologist can offer strategies to help compensate for the hearing loss when communicating or listening to others (for example, ask the classroom teacher for preferential seating so the ear in which the child has hearing faces the teacher and not the window). Audiologists can recommend, monitor and instruct others in the use of hearing aids and auditory trainers.
Nurse:	Interprets and supports the child's medical and/or healthcare needs. Assumes responsibility for establishing a medical management plan which may affect the child's therapeutic and educational programs.
Occupational Therapist (OT):	Traditionally focuses on developing therapeutic methods to aid in activities of daily living, such as eating, dressing, and writing. Occupational therapists assist the team in adapting the home and school environment so a child can participate as independently as possible (for example, the OT might adapt a spoon handle to make it easier for a young child to grasp and hold).
Physical Therapist (PT):	Traditionally focuses on muscle tone, positioning, and helping a child to walk or become mobile with or without adaptive equipment (for example, walker, braces, or wheelchair). Physical therapists assist the team in determining appropriate programs for promoting motor skill development.

Physician:	Provides primary health care and specialized medical care to the child, including both diagnostic and treatment services. Physicians may also be a source of referral to other professional services or resources, such as therapeutic or psychological services, early intervention, or special education.
Psychologist:	Administers psychological assessments to children and interprets their findings to the team. In some settings, psychologists may also provide clinical services or counseling to children and families. Psychologists also develop behavior modification programs to implement in the home and/or school.
Social Worker:	Provides a link to services which support the family's well-being and needs. They play a diverse role, from direct counseling to helping families access community resources for financing, recreation, or community support (for example, respite services, food stamps, home nursing services, parent-support group).
Speech/Language Pathologist:	Evaluates a child's communication abilities. May address the production of speech sounds, including evaluation of the mouth, breathing, oral muscle control, and articulation. Speech/language pathologist is also responsible for developing alternative communication systems for children who are non-verbal (for example, sign language, or picture communication boards). The pathologist assists the team in developing interventions to improve communication skills.
Vision Specialist:	Develops adaptive equipment or programs to improve vision or use existing vision as much as possible. The vision specialist participates in the design of programs to teach independent living skills and mobility training to children who have visual impairments.

Integrated Therapy Model

Special education and related services for children with disabilities should be provided within the context of natural environments (for example, home, day care, nursery school, kindergarten, third grade) and incorporated into natural routines. Related service professionals may provide the service themselves, or they may train and consult with other service providers (for example, parents, regular education teacher, nursery school teacher) to provide the service.

Direct therapy occurs when the therapist works directly with the child on an individual or group basis in the context of natural routines. Direct therapy includes assessment, intervention, implementation, and evaluation. **Indirect therapy** involves training others to perform specific interventions and then monitoring the performance of those interventions on a continuing basis. For example, physical therapist might teach the nursery school teacher how to facilitate rolling for a young child unable to crawl, in order for the child to reach a favorite toy during free play: the therapist cannot be in the nursery school room all the time but the child needs to practice rolling, for mobility during naturally occurring routines. Thus, the physical therapist is providing indirect therapy to the child by training the teacher to implement interventions.

An integrated therapy model is the most efficient and natural way to provide children with disabilities with special education and related services, within natural environments. The integrated therapy model requires a team approach that emphasizes **role release** and indirect therapy services. Role release means sharing and exchanging certain roles and responsibilities among team members. All team members have specific skills and information they can share with others; in role release team members release some functions traditionally associated with their individual disciplines.

The success of an integrated therapy model requires that the team members (for example, special education teacher, speech pathologist, physician, physical therapist, nurse, and parent) work together on an ongoing basis to plan, implement, and monitor the delivery of services to the child. The ingredients necessary for the successful collaboration of professionals form different disciplines are:

- **Attitudes** of team members (their willingness to share information and skills)
- **Accessibility** of the specialists (their availability for consultation and training)
- **Communication** (the specialists reduce their use of jargon)
- **Transmission** of information (the specialists pinpoint relevant information to share with other team members)

Teams should follow an integrated approach to program development and implementation. The special education and related services professionals must work **across disciplines** to share information about the child's program, and be willing to release their roles in order to integrate the goals and objectives of each discipline involved in a child's care. This ensures that a child's individual needs are addressed through a collaborative process within naturally occurring routines and environments.

FAMILY STUDY

Jenny is a fifteen year old single mother living at home with her mother and father. Jenny's mother and father have supported her decision to raise her baby, finish high school, and continue to live with them. They have also agreed to pay for child care when Jenny is in school, since they both work. Jenny's daughter, Maddie, was born prematurely, causing a variety of problems. Most significantly, she has severe vision loss, possibly, she is legally blind.

When Maddie was discharged after two months in the NICU, Jenny was pleased with her progress. Maddie appeared alert and active, and ate well. The discharge plan recommended follow-up opthamalogical exams to monitor Maddie's vision problems, and referred Jenny to an agency that provides early intervention services for infants with blindness/low vision. Since the hospital is about 80 miles from Jenny's rural home, it is very difficult for her to make weekly follow-up appointments. The hospital agreed to have Jenny make bi-weekly visits to her pediatrician, whose office is in a nearby town and who has treated Jenny since she was a child, for follow-up services. The pediatrician, however, has not had any experience with children who have severe vision impairment, nor with early intervention or special education services.

DISCUSSION

As Maddie's primary pediatrician, evaluate the following:

How do you see your role in this situation ?

How do you see your role as Jenny's pediatrician ?

How do you see your role as Maddie's pediatrician?

What qualities do you feel the early intervention program should have, to best meet both Jenny and Maddie's needs?

What other professionals do you think Maddie will need the services of in her early intervention and later special education plan?

What do you need to know to feel more competent to treat Maddie now and in the future?

RESOLVE

The pediatrician met with Jenny and Maddie in his office. He believed the first step should be an informal discussion with Jenny to see how she was adjusting to all the changes in her life - physically, mentally, and emotionally. He thought it was important to see both his patients in a comfortable, non-threatening environment so he could get a sense of how Jenny interacted with Maddie. Next, the doctor asked Jenny if she had any questions about Maddie, such as her stay in the NICU, her vision problems, or general developmental concerns associated with premature births. Once this was done, the pediatrician let Jenny know that he felt very capable treating any of Maddie's medical problems, but that visual impairments was a new specialty for him. They would need to work together, and consult and learn from others who had more expertise in this field.

Next, the pediatrician discussed finding an early intervention program for Maddie. He asked Jenny where she would like Maddie to receive these services and discussed her options: home-based services or center-based services. Jenny said that a neighbor who had a little playgroup for babies and toddlers was willing to keep Maddie while Jenny went to school. Since Jenny wanted to place Maddie in a family daycare situation, the pediatrician understood that more people would need to learn about Maddie's visual impairments. He called the State Department of Education to get information about services available for children with visual impairments. He then gave Jenny the name of the agency to contact and wrote a referral for services based on information from the hospital. With Jenny's permission, he also made copies of any medical documents he felt the agency might need in order to start services for Maddie.

Within a month, Maddie was given an evaluation, by an early intervention team, which determined her to be eligible for early intervention services in the family day care. The evaluation recommended that she receive physical therapy and instruction from a vision specialist (a teacher for the visually impaired), for one hour twice a week. Once Maddie's program was under way, the pediatrician asked Jenny if the physical therapist and vision specialist might use one of their therapy sessions to meet with him in his office to help him better understand how to provide Maddie with care that is sensitive to her visual impairment.

By Jenny's arrangement, the pediatrician met with Jenny, the physical therapist, and the vision teacher. The group believed this meeting was a good opportunity to exchange information and share their expertise with one another, in order to coordinate their service delivery efforts. The physical therapist explained that babies with visual impairments or blindness often seem to dislike being picked up: they may arch their backs, become stiff, or seem to push away. Both Jenny and the pediatrician had seen this reaction in Maddie before. The physical therapist explained that visually impaired babies are often quiet and still much of the time because they are listening to what is going on around them; their reaction to being picked up is related to this keen attention they are giving the world. If they are safe and intent on listening, and suddenly finds themselves being moved around in mid-air, it is natural for them to get upset. The physical therapist suggested giving some kind of warning that Maddie is going to be picked up:

first talk softly, then add a touch of the hand, and then finally, pick her up. The vision specialist also told Jenny and the pediatrician that babies with visual impairments/blindness usually do not receive the visual cues that would warn them of impending discomfort or unpleasant situations such as having their temperatures taken, getting shots, having cold stethoscopes placed on their chests, or wiping their faces and noses. She suggested using a signal, such as, a gentle knock before the activity, to help prevent Maddie's generalized withdrawal, and to keep Maddie receptive to positive human contact. The team members thought that this type of information-sharing was essential to best meeting Maddie's needs; they believed they should meet on a bi-monthly basis to ensure continuity as Maddie grows and her needs begin to change. Jenny suggested including the family daycare teacher, although it would be hard for her to get away. The therapists then said they would share their information with the teacher when they went to the day care. The pediatrician suggested they rotate the meetings, and said he would try to visit the day care.

DISCUSSION - ANSWERS

As Maddie's primary pediatrician, evaluate the following:

How do you see your role in this situation?

- To learn about the integrated therapy model as well as Maddie's individual needs
- To remember that Jenny is still a patient, as well as her daughter, Maddie
- To give Jenny the respect shown to all other parents

How do you see your role as Jenny's pediatrician?

- To ensure that Jenny is adjusting physically, mentally, and emotionally to all the changes in her life
- To make it clear to Jenny that she can ask any question at all, either regarding herself or Maddie

How do you see your role as Maddie's pediatrician?

- To consult with a vision specialist to learn about the particular needs Maddie may have
- To refer Maddie to an early intervention program
- To collaborate with Jenny and other professionals to provide the best possible care for Maddie

What qualities do you feel the early intervention program should have, to best meet Jenny and Maddie's needs?

- A vision specialist must share his or her extensive knowledge about visual impairment
- The physical therapist must have knowledge of visual impairments
- The professionals must respect Jenny as a parent, while being sensitive to her youth
- The professionals must collaborate with Jenny and each other to formulate an IFSP which will maximize Maddie's abilities and assist the family

What other professionals do you think Maddie will need the services of in her early intervention and later special educational plan?

- A vision specialist
- A physical therapist with knowledge of visual impairments
- A social worker

In the future she will need the following professionals in addition to the above:

- Special education teacher
- Psychologist

What do you need to know to feel more competent to treat Maddie now and in the future?

Now:

- Maddie's current age and level of development
- The family needs

Future:

- Maddie's progress, in other areas beside the medical
- The content of IFSP meetings

REFERENCES

Individuals and Disabilities Education Act (1991). P.L. 102-119. (20 U.S.C. Sections 1400-1485.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Role of Other Disciplines Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

CURRICULUM DEVELOPMENT

The basic components of curriculum design should include health care needs to positively affect the development of programs for infants and children with disabilities.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe curriculum design as it pertains to the early intervention and special education of children with disabilities.**
- **Define assistive technology and list examples.**

Children learn and develop at their own pace. A special education classroom or early intervention program, therefore, is structured to meet the varying needs of all the children it serves. The teachers or intervention team staff, and parents, develop a curriculum for each child. The curriculum is an organized set of activities designed to achieve the learning goals set for each child. It outlines both the **content** to be taught and the **methodology** to be used, and thus it is the framework within which teachers and early intervention teams (for example, families, special educators, speech therapists, daycare teachers) work to meet the individual needs of the enrolled children. A curriculum should contain appropriate planning for each student's growth and development within the group structure of the classroom. It should be chosen with a thorough understanding both of the philosophy of child development and of its implications for the child's individual learning needs.

The Individual Family Service Plan (IFSP) and the Individual Education Plan (IEP)

The curriculum for a learner with disabilities is contained in the Individual Family Service Plan, for children up to age three, or the Individual Education Plan, for children age three to twenty-one. The team developing the curriculum should keep the abilities, goals, concerns, and preferences of the learner in mind, and seek to implement the curriculum within the routines and activities of naturally occurring environments. The educational team for students with disabilities (for example, family, special education teacher, regular education teacher, and related service professionals) should collaborate on implementing curriculum goals and objectives; this collaboration will benefit the "whole" child and help ensure that he or she will use in other settings the skills learned in one.

An effective curriculum should address a wide range of the child's interests, and abilities, and provide a variety of activities and materials. The complexity of the work, and the challenges to the children and youth will increase as they master the initial skills targeted in their goals and objectives as stated in the IFSP or IEP.

Curriculum Design

Developmentally Appropriate Practice

Special education programs often use an eclectic approach to curriculum development and service delivery. However, the specific program components of any individual curriculum should be grounded on current theories of development, cognition, behavior, or ecology. One approach to curriculum is to consider it in terms of "Developmentally Appropriate Practice" (Bredekamp, 1987). Developmentally appropriate programs are designed to meet the needs of individual children. The concept of developmental appropriateness has two components: age appropriateness and individual appropriateness.

Age Appropriateness:

> Research indicates that there are predictable sequences of growth and change that occur in all areas of development. Knowledge of the typical development of children assists teachers to plan appropriate experiences and prepare the learning environment. Examples may include a young preschooler with severe disabilities who needs to have sensory experiences and can be helped to play at a sand or water table with peers; a twelve year old with severe disabilities who needs sensory experiences and could be helped to use sand, water, and clay to make a topographical map with peers in his/her seventh grade social studies class.

Individual Appropriateness:

> Each child is, of course, unique. The curriculum and the adults' interactions with the child, therefore, should respond to the child's individual needs. Each child's experiences with peers, adults, and learning materials (such as, toys, books, and computers) should match the child's developing abilities, and expand his/her interest and understanding. The goals for each child should be reached through activities that are child-initiated and directed. The child's learning should not be impeded by adult-established concepts of completion, success, and failure.

Natural Environments

Although a specific disability may primarily affect one part of a child's development (such as vision), other developmental domains also are likely to be affected. A combination of goals is necessary, therefore, to ensure a natural teaching setting and an efficient teaching approach. For example, a child with low muscle tone in the trunk area can work a puzzle with a peer, while a physical therapist helps with muscle control: this situation integrates, the child's motor, social, and cognitive development into one activity, rather than treating them in isolation. This approach improves on past practices in special education, in which professionals concentrated solely on the primary effects of a specific disability; it also allows special education and related services (such as physical therapy) **to be integrated into the child's learning experiences through naturally occurring routines and activities** in the home, nursery school, elementary school, or high school. Naturally occurring routines may include storytime, dressing, playtime, reading groups, art, gym, and so on. This process is called "activity-based instruction."

Activity-Based Instruction

Activity-based instruction embeds the teaching of many skills during one routine/activity <u>and</u> the teaching of one skill across many routines/activities (Bricker & Cripe, 1992). This type of instruction uses naturally occurring events to teach functional and broadly applicable skills. For example, a child can work toward motor, communication, social, and cognitive learning objectives during the routine of free play, while bathing dolls at the water table. This activity can promote communication with another peer (as in, "I want the soap"), social skills (as in, taking turns with the soap), motor skills (for example, reaching and grasping for the soap or washcloth), and cognitive skills (e.g., problem-solving by finding something with which to dry the dolls). Also, one goal in the area of communication (for example, choice-making through pointing) can be taught in a variety of routines: the child can point to a favorite cracker during snack; point to his/her choice of colors for an art project; and point to a favorite book during storytime.

Assistive Technology

A new, exciting, and important addition to curriculum planning for children with disabilities is **"assistive technology,"** legally mandated in The Individuals with Disabilities Education Act, **"assistive technology service"** is defined as:

> "...any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device..."[20 U.S.C. 1401 (a) (26)].

The term "**assistive technology device**" is defined as:

> "... any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or customized, that is to increase, maintain or improve functional capabilities of individuals with disabilities." [20 U.S.C. 1401(a)(25)].

Assistive Technology, then, means access to the use of a classroom computer for a child who cannot write, or providing a child who cannot talk, but who can read, with a touch talker or picture board for communication.

FAMILY STUDY

Marissa was born at a local community hospital. When she was one month old her family noticed waxy-looking pimples on her arms and legs. Marissa's pediatrician referred her to the dermatologist on staff. The results of a biopsy indicated an extremely rare and unusual genetic disorder.

- At six months, Marissa developed a severe seizure disorder.
- At nine months, Marissa's teeth began to grow in abnormally.
- At one year, Marissa's family had her evaluated for early intervention services. The assessment team determined that she was significantly delayed in her language, motor, social, and cognitive development.

Marissa's family enrolled her in a local early intervention program. She received a home-based intervention program for the next twelve months. Then, at twenty-four months, the early intervention team (family, special educator, speech therapist, physical therapist, and pediatrician) decided to enroll her in a nursery school in the community for three days a week. The team felt the time had come to move Marissa's educational services from home into an inclusive, early-childhood program. In this natural environment Marissa could interact with other toddlers and enlarge her learning environment. The early intervention team decided on a neighborhood nursery school philosophically committed to including all children. The team chose a mixed two and three-year-old group and determined that Marissa would receive the support services of special education, speech therapy, physical therapy, and occupational therapy.

The early intervention team met to develop, update, and prioritize the goals and objectives on the Individualized Family Service Plan (curriculum) for Marissa's nursery-school class - - her new learning environment. They discussed the progress she had made thus far, her current abilities, and areas to target for learning. They prioritized the areas to focus on with her: communication and mobility.

Marissa is unable to move independently. The physical therapist believes that Marissa needs this independence, and suggests she use a motorized, adapted go-cart. The other priority set for Marissa is communication skills: although Marissa is able to vocalize, she does not communicate by speech. The speech therapist thinks that assistive technology, in the form of a touch talker, will benefit Marissa. The touch talker will allow her to communicate expressively with her family, peers, and teachers.

Both the priorities for Marissa's individualized curriculum require assistive technology: the touch talker for communication and the motorized go-cart for mobility (see Appendix A for other types of assistive devices). The family senses resistance from the early intervention team and they decide to ask their pediatrician, who has supported Marissa's placement in a natural environment, for a letter strongly recommending that these two devices be listed on her IFSP in order to increase and improve her functional capabilities as a learner.

DISCUSSION

As Marissa's primary pediatrician writing this recommendation, how would you answer:

What is assistive technology?

How does assistive technology relate to Marissa's needs and to the development of her curriculum or IFSP?

How can these devices (the motorized go-cart and the touch talker) be used in the routines of Marissa's nursery school program? (refer to appendix B)

Who could most appropriately help Marissa learn how to use these devices?

What are the specific skills Marissa will be working on, in using these devices?

RESOLVE

The pediatrician is very familiar with Marissa's history, having followed her since infancy. He supports the inclusive environment at the preschool. He has spoken on the phone to the various service providers (speech therapist, physical therapist and occupational therapist, special educator, nursery school teacher, and family) to get specific information for his letter of recommendation to the early intervention program. The team members have informed the doctor that Marissa will need to use a touch talker and motorized go-cart to help implement her curriculum for improved communication and mobility. These are not luxuries but necessities, to which she is entitled by law.

The pediatrician asked the team to send him an activity-based schedule reflecting the use of these devices within Marissa's daily activities at the nursery school. The team sent him a list of specific objectives that Marissa was working on for communication and mobility and a sample of how and when these objectives would be taught (see Appendix B Activity Based Schedule). The team indicated that the pictures they used on the touch talker would reflect the routines, vocabulary, peers, teachers, and family members in Marissa's school and home environments.

The pediatrician reviewed the Activity Based Schedule and agreed that Marissa needed assistive technology to accomplish her Communication and Mobility objectives. Without these devices she would be dependent on others for communicating and for moving around in her environment. This was not acceptable. Thus the assistive technology is an integral part of her curriculum and needs to be written into her IFSP.

DISCUSSION - ANSWERS

As Marissa's primary pediatrician, writing this recommendation, how would you answer:

What is assistive technology?

- Devices and services that enable people with disabilities to function optimally in their natural environments

How does assistive technology relate to Marissa's needs and to the development of her curriculum or IFSP?

- In order for Marissa to be able to participate in the learning environment, she may need assistive devices and/or services
- Marissa's need for assistive technology must be incorporated into the IFSP or IEP in terms of methodology and activity-based instruction
- Without assistive technology Marissa's social development would be limited

How can these devices (the motorized go-cart and the touch talker) be used in the routines of Marissa's nursery school program? (refer to Appendix B)

- The motorized go-cart will enable her to move around the classroom independently
- The touch talker will enable Marissa to communicate more efficiently with peers and adults and will allow her to demonstrate what she as learned
- The devices will both enhance her socialization with peers and her independence

Who could most appropriately help Marissa learn how to use these devices?

- This is to be determined at the IFSP meeting
- Most likely the physical therapist for the go-cart and the speech and language therapist for the touch talker
- Whoever facilitates the use of these devices, they will need to do so in collaboration with the teachers, other service providers and the family

What are the specific skills Marissa will be working on, in using these devices?

- Communication
- Mobility
- Socialization
- Independence

APPENDIX A

Partial Adaptive Equipment List

Communication Devices

- Adapting Switches
- Artificial Voices
- Pointers
- Nonoral Communication Systems (i.e., touch talker)
- Scanners

Items to Facilitate Daily Care

- Bath Seats
- Lifts
- Adaptive Clothing

Mobility Aids

- Scooter Board
- Wheelchair
- Crutches
- Canes
- Walkers
- Reciprocating Walking Brace

Orthopaedic Appliances

- Adjustable Prone Board and/or Stander
- Hand Splints (Static and/or Dynamic)
- Ankle Foot Orthosis (AFO)
- Limb Prosthesis

Positioning Devices

- Bolsters
- Modified Furniture
- Wheelchair Tray

APPENDIX B

ACTIVITY BASED SCHEDULE

Pre-School: ABC Pre-School Name: Marissa

Domain						
Nursery School Schedule of Activities	Gross Motor	Fine Motor	Language	Cognition	Self-Help	Social/ Emotional
Arrival			Marissa will use touch talker to touch two pictures "Hi" and peer's name for greeting		Marissa will use touch talker to press two pictures "I want" and bathroom	
Free Play (blocks, housekeeping, water table, art corner, large toys				When asked where do you want to play, Marissa will use touch talker to press two pictures; play and her choice		
Art			Marissa will use touch talker to indicate her choice of colors for art project.		Marissa will use touch talker to indicate "I want" and help.	
Snack		Marissa will use go-cart forward from center of room to snack table to carry snack to table.				
Outdoor or Indoor large group play	Marissa will use go-cart to move joystick forward to go to slides.					Marissa will move go-cart forward in playground to give peer a ride.
Story Time			When asked to choose a story, Marissa will press touch talker to indicate choice "I want" bears.			
Dismissal						Marissa will use touch talker to say good-bye to a friend.

REFERENCES

Bredekamp, S. (Ed.) (1987). Developmentally appropriate practice in early childhood programs serving children from birth through age 8. Washington, DC: NAEYC.

Bricker, D., & Cripe, J.. (1992). An activity based approach to early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.

Individuals with Disabilities Education Act (1991). P.L. 102-119. [20 U.S.C. Sections 1400-1485].

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Curriculum Development Date ____________________

Please rate the following statements:

	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

NATURAL INSTRUCTIONAL ENVIRONMENTS

Recognize that the environment in which intervention takes place has an impact on the effectiveness of that intervention

Objectives:

Upon completion of this manual, you will be able to:

- Describe how education for children with disabilities in the "least restrictive environment" is protected by law.
- Describe the goal of inclusive education in natural environments.
- List the benefits of inclusion for children with disabilities.

Legal Issues

The school-age child with disabilities was given the legal right to attend public school systems in 1975 through the passage of P.L... 94-142, **The Education of the Handicapped Act.** This landmark legislation mandated the development of Individualized Educational Plans (IEPs), allowing a student with disabilities to receive a free, appropriate education. In 1986, P.L.... 99-457 expanded the education mandate for the child with disabilities to include children from birth to age 21. The Education of the Handicapped Act was renamed **The Individuals with Disabilities Education Act (IDEA)** in 1991; the law now placed an increased emphasis on providing special education services to the child in the **least restrictive environment.** That is, to the maximum extent appropriate, schools must provide special education services to the child in a classroom with the child's non-disabled peers. The child is removed from such a setting only when the severity or nature of his or her disability is such that the child cannot be educated in regular classrooms even with supplementary aids and/or services. When a child receives a majority of his or her services outside of the regular classroom, the intent of the law is to return that student to the least restrictive environments as soon as possible. Additionally, schools must provide a continuum of services, not just one solution or placement option.

To ensure equal access for the student with disabilities within the public school systems, The **Americans with Disabilities Act** of 1990 (ADA) stipulates that schools provide such public accommodations as ramps and accessible stalls in school restrooms for the student with mobility limitations. The law also requires that the student have equal access in learning situations, under the term **"reasonable accommodation"**. Under ADA, for example, it is reasonable in today's computerized society for a student with limited mobility of his or her hands to be provided with a computer.

For children under the age of three an additional consideration is the **natural instructional environment.** In states that participate in Part H of IDEA (early intervention for infants and toddlers), the infant or toddler must receive services in his or her natural environment, in accordance with the Individual Family Service Plan. Natural environments may include the home or settings in which children without disabilities participate. Part H also requires transition planning to aid in the movement of the child from early intervention programs to special education programs within the local school district. Transition planning should begin three to six months prior to the child turning three.

The concept that all children can be taught together while still meeting each child's individual needs has required a sometimes difficult adjustment for many special education, early intervention, and "regular" education professionals. In thinking back to our own school experiences, the majority of us were exposed to traditional teaching methods, curricula, and learners. The child with disabilities was rarely a part of our educational experience, and in many schools there was little variation in teaching style or adaptation to individual differences. School officials usually assumed that all children at a given grade level should meet the same skill levels and master the same curriculum.

Inclusive Education

The goal of inclusive education in natural environments is to ensure that each child is accepted as an equal classroom member, recognized for his or her abilities, and provided with an appropriate educational program and any supports necessary for the child to be a successful learner (Stainback & Stainback, 1992). This pertains to the child who has been labeled severely or profoundly mentally or physically disabled, disruptive, chronically ill, medically fragile, atypical, gifted, or at risk. All service providers and educators need to incorporate into their philosophy about education the value of providing the child with disabilities the opportunity to learn in natural environments/inclusive settings. Some of the major benefits of inclusion are:

- The child with disabilities who is provided with the necessary support services will be able to participate in and have the same types of experiences as children without disabilities, while still having individual needs met
- Opportunities in natural environments increase the likelihood that a child with a disability will learn how to interact with the real world: no child should be denied this opportunity
- Research shows that the early years of life are critical for learning and growing. Natural environments, such as integrated early childhood programs, are better suited to meet the needs of each child, and to enhance the child's potential
- Early childhood programs provide natural environments that are flexible, open, challenging, accepting, growth-producing, and individualized
- Children learn from their peers

- Natural environments (for example, daycare, preschool, kindergarten, regular elementary, middle and high school grades) provide broader options and choices in all areas (play, social competence, language, curriculum) than segregated classrooms focused on children with delays or disabilities

FAMILY STUDY

Jason is 36 months old and lives at home with his parents and four siblings. His father is in the construction business and works on and off, depending on the availability of jobs; he also plays in a band on weekends. The older two children have afterschool jobs and help contribute to the family income. Jason's mother is not now working.

Jason was born six weeks premature and was hospitalized for two months after birth because of a prenatal viral infection. At birth, Jason experienced repeated episodes of respiratory distress and severe feeding difficulties. At 36 months of age, Jason has:

- Very stiff muscles
- Vision problems
- Severe brain damage
- A communicable disease: people in contact with him have to be cautious
- A gastronomy tube for feeding
- He requires occasional suctioning at home, for which the family has a machine
- Jason is often irritable and cries frequently
- Jason uses adaptive seating and undergoes a variety of positioning techniques to minimize his discomfort and facilitate some independent arm movement for playing and exploring toys
- Jason is able to let his family know when he is uncomfortable by crying; he lets them know when he is happy or enjoying them by vocalizing and smiling

Jason receives his medical care at the city hospital and goes to specialty clinics (for example, for adaptive equipment and orthotics) at the children's hospital . The family pediatrician has been caring for the family for 17 years. The family feels comfortable with him and found him to be helpful, informative, and supportive when Jason was born. The pediatrician currently coordinates all of Jason's medical care.

Jason has been receiving early intervention services through a state early intervention program since he was six months old. The early intervention program provides both direct services and indirect consultation to infants and toddlers in the home. As required by law, the program also provides these services to children, usually from 18 to 36 months, in natural community environments such as daycare and/or nursery school programs. The decision about where a child should receive his or her services is made by a team during the Individual Family Service Plan (IFSP) process, with the family, early interventionists, and any other people who are an integral part of the child's life (for example, nurse, physician, grandparents, baby-sitter) participating.

Currently, the early intervention program has been providing Jason with services three mornings a week in his neighborhood nursery school. He receives onsite services from a special education teacher, as well as occupational therapy and speech therapy once a week. He receives physical therapy at home three times a week through a rehabilitation program. Through the Board of Education Services for the Blind (BESB) a vision teacher provides Jason with consultation services once a month at the nursery school. Many of Jason's medical needs are monitored through nursing services provided by the early intervention program. A nursing consultant goes to the nursery school three mornings a week, while Medicaid provides Jason with nursing in his home on the other two mornings. Both of these professionals give Jason the medical attention he needs, such as medication and suctioning.

Jason's parents believe he has been positively challenged through his early intervention services in this inclusive natural environment; they also think he has had wonderful opportunities for socialization and interaction with his peers in the community. Since Jason has been in a neighborhood nursery school, his mother has met some of the other mothers at gatherings and meetings; this contact has led to weekend playdates for Jason with some of his schoolmates. The children sometimes come to Jason's house, and sometimes Jason goes to their houses. Jason's mother is thrilled that the families she has met have been friendly, open, supportive, and non-judgmental. Jason's parents also think that much of what he has been able to accomplish (for example, moving his arms to explore toys, vocalizing to get attention, eating with a spoon, using assistive technology, and responding to other children) is directly related to his receiving services in the inclusive early intervention program at the nursery school. Jason's parents feel very strongly that they would like his future learning experiences to continue in this direction.

Since Jason is 36 months old, the responsibility for his program and service provision will transfer from the early intervention program to his local school district, and his parents and the professionals involved with him have began planning for this transition. Jason's parents would like the school district to continue providing his special education and related services in his nursery school, as has been done by the early intervention team. His parents have had meetings with officials of the school district, who have told them that the school district does not offer this type of service in the community, especially for youngsters with severe multiple disabilities. The district officials explained to Jason's parents that their special education preschool program is in the local public school, where Jason can be in a class with six other children. These children also have serious medical problems and are at Jason's level of functioning. The school district has a nurse at this program who can monitor Jason's medical needs full-time.

Jason's parents strongly believe that Jason should be given the opportunity to continue his education in a natural environment such as his nursery school. He has made wonderful progress there, and the early intervention team agrees strongly that Jason should continue to receive services in the nursery school. The early intervention team will support the family as it advocates this placement with the school district. The family pediatrician has also been pleased with Jason's experience in the nursery school. Jason's planning and placement team (PPT) meeting with the school district officials is scheduled for the following month. Jason's parents think that they should begin to plan for and seek solutions for some of the problems and barriers his severe disability and his medical problems seem to present to the school system. Jason's parents have made an appointment with the pediatrician with whom they are most comfortable, in order to solve some problems before the meeting.

DISCUSSION

As Jason's primary pediatrician, evaluate the following:

In what ways does Jason benefit by receiving his early intervention and related services in a natural environment such as the nursery school?

What are some of the medical problems Jason has that make the school district officials think they cannot meet his needs in a natural environment?

The family comes to you, the pediatrician, for help in solving some of the obstacles the school district officials are raising about Jason's medical concerns. What are some of the possible solutions? What strategies might you undertake?

RESOLVE

Jason's parents met with their family pediatrician to address some of the barriers the school district was raising to deny Jason educational services in an inclusive environment. The first concern the family shared with the doctor was that Jason would continue to need nursing support in his nursery school. The early intervention program was currently providing direct nursing care for Jason on the three mornings he was at nursery school, but when Jason transfers to the school district he will no longer be entitled to nursing care, since the funding source will change. The pediatrician examined Jason's nursing care situation: during the times when Jason was not in the nursery school (two mornings a week), he received nursing at home through Medicaid. Jason's home state allows Medicaid nursing services to follow the child. The pediatrician therefore realized that he could increase Jason's Medicaid nursing to five mornings a week, thus providing the service in the nursery school. This should eliminate any concerns the nursery school and school district officials have about monitoring and meeting Jason's medical needs.

Next, Jason's parents explained to the pediatrician that Jason was now entitled to receive his educational services five half-days a week through the school district. The pediatrician thought that for the time being Jason should continue to attend the nursery school only three days a week, as he was doing well both physically and emotionally, and as many "typical" three-year-olds attend nursery school on a part-time basis. Jason's mother agreed and was comfortable with this idea, especially since she enjoys having him at home the other two mornings. She will continue to arrange playdates for him with his friends.

The pediatrician also made suggestions for some of Jason's specific medical needs, such as suctioning and tubefeeding. He believed that Jason's educational planning team should consider interventions in the nursery school so as to decrease Jason's need for these services over time. He suggested, for example, that the speech therapist look at an eating program to increase oral motor development; he thought such a program could be implemented both at home and during snacktime in the nursery school. The family and professionals could eliminate the tubefeeding in school and concentrate on building up Jason's oral motor skills. The pediatrician said he would be willing to call the speech therapist to work out some possibilities.

The pediatrician also believed the physical therapist might be able to introduce some positions in the nursery school that would not interfere with Jason's play skills but that would facilitate postural drainage and thus reduce the amount of suctioning Jason needed during the morning. The pediatrician offered to call the physical therapist to discuss and plan some interventions.

Finally, the pediatrician agreed with the family's observation that Jason had made great improvement and gains in the inclusive nursery school environment; he believed Jason to be content, happy, growing, and learning in this environment, despite his complex medical needs. The pediatrician therefore agreed to write a letter to the school district, strongly recommending that Jason continue to receive his educational program and related services in the nursery school.

Jason's parents left the pediatrician's office with possible solutions and strategies, new goals, and a strong recommendation for inclusive education. The pediatrician had provided a solution to the nursing situation, which was the most critical barrier to Jason's remaining at the nursery school. He also looked at long-term strategies to reduce the medical care Jason needs. All of these solutions, strategies, and goals meant collaborating with the local school district and, most importantly, looking at ways to implement these interventions within the nursery school environment. And, finally, the pediatrician thought that a letter with his strong recommendation to maintain Jason in his current placement was important.

DISCUSSION - ANSWERS

As Jason's primary pediatrician, evaluate the following:

In what ways does Jason benefit by receiving his early intervention and related services in a natural environment such as the nursery school?

- Within the least restrictive environment, Jason would have access to the same broad range of experiences as his non-disabled peers
- It promotes acceptance and equality, as well as recognition of <u>abilities</u> rather than disabilities
- It complies with the law

What are some of the medical problems Jason has that make the school district officials think they cannot meet his needs in a natural environment?

- How to protect themselves and the other children from the communicable disease Jason has.
- Having to manage the feeding tube and Jason's need for suctioning, as well as, adaptive technology.

The family comes to you, the pediatrician, for help in solving some of the obstacles the school district officials are raising about Jason's medical concerns. What are some of the possible solutions? What strategies might you undertake?

- Set up a meeting with the physician, the family, and the current early interventionists to provide school officials with education and information regarding:
    - a) Jason's medical needs, and who can attend to them within the school
    - b) Precautions to take for the communicable disease
    - c) How current service providers have addressed these concerns
    - d) What has helped Jason be so successful in his current program

REFERENCES

Stainback, W., & Stainback, S. (1992). Schools as inclusive communities. In S. Stainback & W. Stainback (Eds.), Controversial issues confronting special education: Divergent perspectives. Boston, MA: Allyn and Bacon Publishing Co.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Natural Instructional Environments Date ____________

Please rate the following statements:

	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

SERVICE COORDINATION

Service coordination enhances the team's ability to meet the family's needs.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe service coordination.**
- **Describe how service coordination assists physicians treating children with disabilities or special health care needs.**

Families who have children with disabilities or special health care needs often face a fragmented, compartmentalized, and difficult to access system of services for their children. These services have been developed haphazardly, in response to social, political, economic, scientific, cultural, and other factors over the years, without the benefit of a strategic plan. In service coordination, this lack of planning, or organization, is addressed by one individual who is knowledgeable about the complete service delivery system and who is designated by the lead agency in early intervention. The function of the service coordinator is to assist families in finding and using the needed services and supports.

Service Coordination

Service coordination is a new way of planning services for children with disabilities and their families. In traditional case management, each service or agency (for example, rehabilitation, school services, health) had its own case manager to oversee the services provided by that particular agency, and the progress made with those services. These programs developed case management systems to address their own administrative convenience and efficiency, rather than to address individual family needs, and preferences within the community. The case manager often served as the gatekeeper, monitoring the use of resources within that agency. This was done with little or no input from the family and, consequently, these case managers were often ineffective in meeting the needs of families. As a result, a member of the family often assumed the role of service coordinator, planning and overseeing their own services and supports, even though she or he was not officially recognized in this role.

Service coordination replaces the concept of case management, under P.L. 99-457, for children from birth to three years of age. Under P.L. 102-199, Section 303.6, service coordination is broadly defined to include the following:

> "The activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards and services that are authorized to be provided under the state's early intervention program. Service coordination, also includes identifying, accessing, coordinating and monitoring other services which the child and family may need."

The intent of the law is for the service coordinator to help parents take charge of the issues that are important to them. The service coordinator is the single point of contact for the family and the service providers.

Referral Procedures

A referral for early intervention services can be made by parents, physicians, teachers, or other involved indivduals. To initiate a referral, call the number designated by the lead agency. Upon referral a trained service coordinator will be assigned to the family as provided by the law. In some cases the service coordinator is selected from the program or agency most directly involved with the child; in other cases the coordinator is independent of the early intervention programs, but knowledgeable about the priorities and concerns of this particular child and family. The service coordinator can also be the parent of a child with special needs. Part H stipulates that service coordination will be available at no cost to families with eligible children.

A family-centered model of service coordination requires that families be able to chose their service coordinators from a pool of trained service coordinators. Best practice dictates that this person should be neutral, that is, not providing direct service to the child and family.

Leaders in education, health, mental health, parent networks, and human services are enthusiastic about the potential of service coordination, as it will play an important role in a shifting from the traditional model of service delivery to a more individualized, collaborative and family centered system. Under such a system, integrated community-based services will be available to the children and their families. These families will be assisted and supported by a pool of trained service coordinators.

For physicians treating children with disabilities or special health care needs, the implications of service coordination are significant. The service coordinator will provide the physician with an easy way to have meaningful input into a child's overall care plan, for the service coordinator can integrate the child's health needs into the broad plan of care in the community. This system thus asssures the physician as well as families of easier access to the services and supports the child needs.

FAMILY STUDY

Lynn is two years old and is in a community daycare program. Lynn lives with her father, Al, and a nine-year-old sister. Lynn was delivered at 33 weeks gestation, following a car accident in which her mother was killed. Lynn's care involves many professionals and community resources. She receives her services through a variety of agencies, and often her father alone must coordinate and plan them.

Al works full-time as a salesman, and because of his schedule, he has difficulty attending meetings and scheduling appointments for Lynn. He often has to miss work and lose pay in order to meet all of Lynn's requirements. His sister lives nearby and helps out with some of the daily chores, like grocery shopping, but she feels that she is not knowledgeable enough about Lynn's health issues to take her to appointments or attend meetings for her. She does provide Al with a great deal of emotional support, however.

Last month, Lynn had two appointments with her pediatrician because of an infection, an appointment with her neurologist, an eye examination, a fitting for her wheelchair, an Individual Family Service Plan (IFSP) meeting, a visit from the DMR social worker, and a meeting with the case manager from the Home Health Agency. Each of these appointments was scheduled at a different time, on a different day. Al lost a total of 26 hours from work, without pay; his boss informed him that he could no longer take this much time off on a regular basis. Al is concerned that he must now choose between Lynn's care needs and his much-needed job.

To make matters worse, Al's insurance will no longer cover Lynn's occupational and physical therapy at Easter Seals, and may only cover some of the home health care which Al needs in order to work. He has discussed these issues with his social worker at DMR, but the social worker did not offer him any real assistance or solutions. Al then told Lynn's doctor that he would have to discontinue her therapy. He is also afraid he will lose his job if he loses the home health care, since the aide stays with Lynn before and after day care. Lynn's doctor is concerned that Al may not be able to continue to care for Lynn on his own.

Lynn's services include the following:

- home health care (32 hours per week)
- early intervention teacher visits (once per week at day care)
- occupational therapy (twice per week at Easter Seals)
- physical therapy (twice per week at Easter Seals)
- speech therapy (twice per week with a private provider)
- day care (five half days per week)
- case management services from Department of Mental Retardation
- respite funds from the Department of Mental Retardation
- case management services from the Department of Health Services
- benefits management from the insurance company
- social services from Easter Seals
- social services from the children's hospital
- case management from the nursing agency

- a minimum of three specialty appointments per month, including: (ophthalmology, neurology, orthopedics/cp clinic, pediatrics for numerous ear infections/colds, orthotics/adaptive equipment

DISCUSSION

As Lynn's primary pediatrician, evaluate the following:

What challenges do you see in coordinating services for Lynn?

What strengths does the family have which might assist those coordinating services for Lynn?

Who might act as the service coordinator?

How will service coordination benefit your to treatment of Lynn and your work with her family?

RESOLVE

Al and Lynn's doctor met to discuss her care and the family's situation. In addition to his general concerns about meeting Lynn's needs, her doctor was concerned that Lynn's father appeared tired and stressed.

Al and the doctor agreed that it would be helpful for the service providers to meet to discuss Lynn's services and, develop strategies for better coordinating and planning them. Al thought that the social worker from the children's hospital would be the best person to coordinate such a meeting. Together, Al and the doctor identified the appropriate medical information to send to the hospital social worker; the doctor sent a copy of these reports to Al as well. The doctor also wrote a cover letter with the reports and spoke with the social worker over the telephone, urging her to convene the meeting, and to discuss the details of planning it with Al. Although the doctor was unable to attend the service coordination meeting, he and Al did discuss the medical services which Lynn was going to need; they also discussed the reports which had been sent from other providers.

The service coordination meeting was held over lunch, so that Al did not have to miss any work time. The meeting's purpose was to address Al's concerns regarding Lynn's care and to establish an appropriate service coordinator. The following people were present:

Al
Al's sister, Janice
a representative from the home health care agency
the physical therapist from Easter Seals

the DMR case manager
Al's parent advocate
the social worker from the children's hospital
Lynn's daycare provider

Lynn's father began by listing his appointments over the last month. In a letter, Lynn's doctor commented that he felt that some of the problems of fragmented care could be addressed if as many appointments as possible were scheduled for the same day. Al had already contacted the social worker at the hospital to discuss scheduling. In addition, the team thought that many of the remaining scheduling issues could be handled by the nurse/case manager from the home health agency, who could coordinate all of Lynn's services with the various physicians. Lynn's doctor had told the hospital social worker that he would be available to consult on this matter.

The group then discussed Al's loss of certain insurance benefits. The parent advocate agreed to visit Al and Lynn one evening to review Al's eligibility for public funding for portions of the home health care, and to discuss options for therapy. The team agreed that, based on Al's income, he may be eligible for services through the State Health Department, and possibly eligible for Medicaid. The parent advocate will assist Al in understanding the process and in filing these applications. The group also agreed that the home health agency would clarify the existing insurance coverage for home health services.

Lynn's doctor had said that while he would not be able to attend meetings to coordinate care, he would consult with the service coordinator on the coordination of specialty services and continued planning of Lynn's medical needs. Although Al would like to take on the role of service coordinator, he may need assistance because of his work schedule. Al's sister agreed to assist him in this, she also said she would be more willing to assist in Lynn's care if someone could go with her to some of Lynn's appointments until she has a better understanding of Lynn's needs, and thus can be an effective advocate for her niece. Both the case manager from DMR and the parent advocate said they would be willing to assist in this process. The team agreed that Lynn's aunt's participation would aid in the transportation to appointments, but that scheduling still needed to be better coordinated. The team agreed to meet again in one month to review the service coordination plan. The home health agency agreed to host the meetings and to send out minutes to all the participants.

DISCUSSION - ANSWERS

As Lynn's primary pediatrician, evaluate the following:

What challenges do you see in coordinating services for Lynn?

- Services are provided by many agencies and health care providers
- The service providers are not functioning as a team and there is no appointed service coordinator
- There may be ways that more of the services could be provided "under the same roof," (i.e. within the school)
- Lynn's father, Al, is in a bind regarding his employment, the need to have continued insurance coverage, and the need to be available for Lynn's appointments
- Al's possible loss of essential services and funding sources
- The amount of time required for, and transportation to, all of Lynn's appointments
- Al appears to be extremely stressed despite his emotional support

What strengths does the family have which might assist it in coordinating services for Lynn?

- Al is clearly devoted to Lynn and wants to assure that all of her needs are met
- Al's sister provides emotional support and assistance with some of the daily routine
- Al is very knowledgeable about the resources available in the community

Who might act as the service coordinator?

- Al, with his sister's support, so it would not pose a threat to his employment
- One of the case managers from DMR, DHS, the nursing agency, or the children's hospital
- Al's sister with additional support
- A trained service coordinator as provided for in Part H of IDEA

How will service coordination benefit your ability to treat Lynn and work with her family?

- It will allow Lynn to receive effective, comprehensive treatment involving several disciplines
- I would gain knowledge of specific, non-medical goals and objectives for Lynn and her family
- Since service coordination includes identifying accessing, coordinating, and monitoring all services, Lynn and her family would be under less stress and receive more comprehensive care.

REFERENCES

Individuals with Disabilities Education Act (1991). P.L. 102-119 (20 U.S.C.) Sections 1400-1485.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Service Coordination Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

TEAM PROCESS

Understand that successful interventions require all providers to function under a common philosophy with shared goals

Objectives:

Upon completion of this manual, you will be able to:

- **Distinguish between multidisciplinary, interdisciplinary, and transdisciplinary teams.**
- **Describe how the successful team process influences the life of a child with disabilities or special health care needs.**

A Child with disabilities may require the services of a wide variety of professionals (Bailey, 1989); those having medical, therapeutic, educational and developmental, and social service expertise may all be needed to 3 establish and implement a viable intervention program for an infant, young child, or adolescent. In addition to the individual needs of the infant or child, the emphasis and location of the program will further dictate professional staff needs. Whether such services are provided through an interagency or intra-agency team, the professionals involved will have to adopt a team model to ensure collaborative service delivery (McCollum & Hughes, 1988); they must be prepared to fully meet the self-identified needs of the family, as those needs relate to the child with disabilities. Their success will depend on the way the team functions.

The provisions of IDEA (Individuals with Disabilities Education Act for Children 3-21) and Part H of IDEA (for Infants and Toddlers, Birth to Three) require that both the assessment and the IFSP or IEP be completed by a multidisciplinary team consisting of the family and professionals from more than two disciplines. Such a group of individuals does not become a functional team merely by bestowing the label of "team" on it, however: rather, a group of people becomes a team when their purpose and function are derived from a common philosophy with shared goals (Maddux, 1988).

Models of Team Process

The types of teams that typically serve young children with disabilities have been identified as multidisciplinary, interdisciplinary, and transdisciplinary. On a **multidisciplinary team**, the professionals represent their own disciplines and provide their own assessments and interventions; these may include report writing, goal setting, and discipline-specific direct intervention for the child and/or the family. The parents are invited to share information with the professionals, while the professionals share the information from their assessment, intervention, and follow-up with the family through an "informing" conference. On a multidisciplinary team the family is a passive recipient of information about their child and professionals do little crossing of discipline lines, making it very difficult to develop and coordinate comprehensive programs for families and their children (McCormick, 1979).

On an **interdisciplinary team** each of the professionals carries out specific disciplinary assessments and interventions. The professionals and the family have a formal commitment to the sharing of information throughout the process of assessment, planning, and intervention (Bailey, 1984), and, usually, one team member is responsible for coordinating the child's services. The interdisciplinary team does some joint decisionmaking, but may have only minimal ongoing communication between team members and the parents.

By contrast, the members of a **transdisciplinary team,** share roles and systematically cross discipline boundaries (Hanson, 1989; McGonigal, 1988; Raver, 1991): this approach was originally conceived of as a framework within which professionals could share important information and skills with a child's primary caregivers. The transdisciplinary team develops a comprehensive intervention program in which a child's developmental needs are integrated across the major domains of communication, motor skills, and cognition (Hutchinson, 1978). The transdisciplinary team model also decreases the number of professionals from different disciplines with whom a child must deal on a daily basis (Rainforth, York & Macdonald, 1992). Further, in the transdisciplinary model all members of the team, especially the parents, participate in a continuous-give and-take on a regular, planned basis. Professionals from different disciplines teach, learn, and work together to accomplish a common set of service goals for a child and his or her family. The role differentiation among disciplines is defined by the needs of the situation, as opposed to the requirements of a specific discipline; designated members of the team jointly carry out assessments, interventions, and evaluations. The transdisciplinary model involves a greater degree of collaboration than other service models, however, and for this reason it may be difficult to implement.

In a transdisciplinary team model, the child's program is primarily implemented by a single person, or a few people. Team members from the various disciplines provide ongoing assistance by both direct service and by consultation. In most early intervention and special education programs, the teacher and program assistants take on the major direct-service role, but at times it is also appropriate for this role to be assumed by a special education teacher, who may provide services within the early childhood program on a regular basis. Support staff from related services most commonly therapists and health care workers, often serve as consultants. This does not mean that therapists stop providing direct services to the child; in order for therapists to be effective consultants, they need to maintain direct contact with the child. This team model should never be used as a strategy to justify reducing the support staff.

Although the transdisciplinary model may appear simple in concept, its implementation can be difficult. People tend to raise barriers to using a transdisciplinary team because of the differences between this and the more familiar, traditional teams. Such barriers may be philosophical, professional, interpersonal, or administrative (for a thorough discussion of these, see Orelove & Sobsey, 1991). In particular, the time commitment required to effectively implement a transdisciplinary team model across all disciplines may be prohibitive for early childhood programs. At a minimum, however, service delivery by more than one discipline requires a commitment to team process.

Effects of the Team Process

A functional team can overcome barriers, maintain the motivation to accomplish its mission and goals, and persevere to foster positive interactions among its members (Dyer, 1977; Starcervich, 1990). A number of variables contribute to effective team process, and are explained (Shonk, 1982) below.

Team Composition. The program or agency affiliation of the team members will exert a large influence on the team process. For example, the resources available to the team will depend on the participating staff, programs, or agencies. These resources can include not only skills and money, but administrative support and time. Teams with fewer resources will need to be more creative in identifying ways to achieve their goals.

Team Goals. Teams must devote time to identifying their goals and objectives. A truly effective team process can only exist when members share the responsibility for accomplishing common goals. An effective team will:

- **Set goals that are clearly understood and communicated to all team members.**

  A collaborative philosophy or mission is the team's overall reason for existence. It provides the team with a focus for its actions. A written statement of the collaborative philosophy will clearly delineate the transdisciplinary and interagency direction. A team will function effectively to the extent that its philosophy is clear and agreed upon.

- **Have ownership of the goals and participate in setting them.**

  All the team members (including the family) need to feel that their input is valued. This helps to ensure that the goals are supported by everyone on the team.

- **Set goals that are clearly defined and measurable.**

  Goals must be written in such a way that everyone has a clear understanding both of what is expected, and how successful mastery of these goals is to be determined and measured.

- **Share individual or personal objectives with one another.**

  Since teams are comprised of individuals, it is important to respect each member of the team.

Team Members and Roles. In order for teams to be effective, each individual must have a clear role and identified responsibilities: ambiguity is a great source of conflict. Team members must, therefore, continually clarify their roles.

In addition to the specific professional roles, responsibilities, and contributions of team members, members will have to assume other roles with regard to team development, leadership, maintenance, and problemsolving. These roles, or functions, must be established within the group in order for the team to work effectively.

To make their team process effective every team member has the responsibility to:

- Share expertise with other team members
- Offer recommendations for addressing a child's needs from their professional perspective or area of expertise
- Listen actively and communicate well. Be clear and concise when reporting information and avoid the use of jargon that other team members may not understand.
- Recognize the contributions of other team members, and encourage their sharing of information.
- Prepare the family for their role on the team and encourage their active participation.

Team Work Style. The team's work style will affect its development and overall effectiveness. In particular, the team will make effective decisions more consistently by using systematic problemsolving. If a team's problemsolving process is "haphazard, unconscious, or less than thorough" (Shonk, 1982), it is less likely to make decisions that will be optimum and appropriate. The team's problemsolving style will also affect how it implements its decisions. When a team applies a formalized, systematic problemsolving strategy, the probability of their achieving an effective outcome increases. Systematic problemsolving will ensure members are satisfied with, and committed to, the decisions they make.

Among the variety of problemsolving models that have been developed is PROJECT BRIDGE (Prentice & Spencer, 1986), a five-step decisionmaking model for teams. Each step in the problemsolving process should be used as a checkpoint for teams to evaluate their ideas and practices in terms of "best practices" for "exemplary services" in the field of early childhood special education. The steps outlined in PROJECT BRIDGE include:

- Problem Formulation and Information Gathering. The problem must be described in clear and observable terms. Resources should be identified, and the team should focus on the facts, rather than opinions.
- Generating Proposals for Solution. As many alternatives as possible should be generated from all participants. Without being judgmental, the team must build positively on all suggestions.
- Selecting Alternatives and Testing Solutions. The team must judge the available resources, and evaluate the alternatives for the solution. The team should decide whether or not the solution makes good use of the resources, is cost effective, and fits the needs and goals involved.
- Action Planning and Implementation. The team should assign specific responsibilities to individuals, determine timelines, and develop procedures for monitoring the plan. The plan is then communicated to all relevant professionals.
- Monitoring and Evaluation. The team should determine how to measure the success of their decision. The team should select a unit of evaluation, decide how often to evaluate, and plan to modify the plan as needed.

Problemsolving, as well as other team tasks, should occur during planned meetings. The team must work face-to-face in order to function its best. Thus, meetings are the hub of the team process. The team meeting can facilitate completing the team's tasks and achieving its goals. The well-functioning team meets at regularly scheduled times, with all team members attending. It is essential that all team members communicate regularly. An effective team meeting begins with a stated purpose or goal, as reflected in a written agenda. This agenda should be distributed before the meeting so that team members can prepare to discuss the issues that it describes. Structure and rules keep the meeting moving. These rules should establish participants' roles (including those of facilitator and recorder) and responsibilities, time frames for topics, and confidentiality policies. The minutes of the meeting record recommendations for action and for follow-up.

Team Leadership. A team is, of course, comprised of individuals who are products of their past experiences and have different attitudes, values, and beliefs about the world. These individuals also have expectations about the team, how it should function, and what it should accomplish. Because the personalities of the team members can ultimately determine the team's effectiveness, team leaders must adapt to meet team members' diverse needs and workstyles. The team leader must foster a climate in which all members feel free to contribute their ideas, express differing viewpoints, and offer solutions to problems.

Teams may have a formal leader who is assigned, appointed, or elected by the group, or an informal leader who may have emerged because of his or her influence, knowledge, skill, or personal qualities. The team may also informally accept someone as a leader because of ineffective formal leadership; often, both leaders operate simultaneously. Problems can occure if team members ignore these informal and formal roles, or misappropriate the functions of each. A team leader has a number of roles or functions with regard to a team's development, the main one being to focus the team on its responsibility to ensure the effective delivery, to the child with disabilities, of collaborative intervention services.

FAMILY STUDY

Polly is 18 months old and lives with her family in central Connecticut. She was born prematurely, and is the sole survivor of a set of triplets. Polly was hospitalized for 13 months following birth; her medical and developmental conditions include:

- Brain damage
- Heart problems
- Frequent infections that result in hospitalizations
- A dependency on oxygen
- Self-abusive episodes, including severe headbanging.

Because of her condition, Polly and her family have been receiving a variety of services since her return from the hospital. These include:

- Health care through her primary pediatrician
- Occupational therapy once per week
- Speech therapy once every other week
- Physical therapy once per week
- Home education through a Regional Education Service Center (RESC) twice per week
- Sixteen hours a day of home nursing care
- Medical supply vendors for special formulas and oxygen
- Specialty care at the hospital through a variety of clinics.

The family regularly has many professionals coming and going out of their house: during the five months that Polly has been home she has encountered five therapists, two teachers, ten nurses, and a hospital-based team comprised of a physician, two nurses, a psychologist, a full range of therapists, and a social worker. Also assigned to Polly's "case" are two social workers, three program supervisors, and three case managers from three separate agencies.

It is not surprising that Polly's parents are often caught in the middle of conflicts among the various professionals; each of whom seems to have a different opinion about Polly's needs, appropriate treatments, payment options, and service schedules. For example, each of the family's three case managers gave the family different information about their eligibility for various sources of public funding, including the Medicaid Waiver; as a result, their application for benefits was delayed and they had to pay several thousand dollars out-of-pocket for the cost of some of Polly's care. In addition, the nursing agency and the different therapists disagree about the amount of therapy Polly needs, and therefore do not cooperate with one another. Because there is no coordination among the service agencies and providers, the family finds that the services Polly receives often cause confusion in their lives. A week in their house looks like this:

- Monday: 16 (hours) nursing/teacher/supervisor/ Department of Income Maintenance case manager
- Tuesday: 16 (hours) nursing/OT/DMR case manager
- Wednesday: 16 (hours) nursing/teacher/clinic visit at tertiary care hospital/PT
- Thursday: 16 (hours) nursing/PT/vendor delivery/ nurse supervisor/teacher
- Friday: 16 (hours) nursing/speech therapy/ adaptive equipment fitting at tertiary care hospital

- Saturday: 16 (hours) nursing
- Sunday: 16 (hours) nursing

The family has concluded that caring for Polly is **not** the primary cause of their stress, but rather that the multiple layers of fragmented services are causing much havoc in their family. Polly's parents are now seeking out-of-home placement for her because they feel that they need to put some order back into their lives. Neither parent feels "functional" with so many people in and out of their house. In Polly's case, one of the purposes of P.L. 99-457, reducing the likelihood of institutionalization, has not been realized.

DISCUSSION

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

What are the family's concerns, priorities, and resources?

What are the service providers' concerns, priorities, and resources?

How can this group of people be shaped into a team? What would their goals be?

What type of team would best meet the needs of Polly and her family? Why?

What should the service team do to assist the family?

RESOLVE

The team which is providing services to Polly represents both interagency and intra-agency professionals. In order for them to provide transdisciplinary services, the members of the service team will have to collaboratively develop a service structure which accomplishes the IFSP goals, according to the family's schedule and priorities. One practice the service team must initiate is a regular time for meeting, during which they can identify mutual goals and service strategies. Since the nurses are the professionals in most frequent contact with Polly, it seems reasonable to the team to suggest that the nurses (along with Polly's parents) provide her with primary service delivery. In this scenario, the therapists and teachers will monitor Polly, but focus most of their effort on the training and support of the nurses and parents through consultation. The key to the success of this model will be the ability of the members to commit the time necessary to build relationships and release their roles for the benefit of Polly and her family.

DISCUSSION - ANSWERS

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

- Occupational therapy, once a week
- Speech therapy, once every other week
- Physical therapy, once per week
- Nursing care, sixteen hours per day
- Oxygen

What are the family's concerns, priorities, and resources?

- Coordination of services among service agencies and providers
- Being caught in the middle of conflicts among professionals
- Health-care financing
- Too many people in and out of their home
- Out-of-home placement for Polly

What are the service providers' concerns, priorities, and resources?

- Appropriate treatments
- Service schedules
- Payment options

How can this group of people be shaped into a team? What would their goals be?

- They must meet together as a team to collaboratively develop a service structure which accomplishes the IFSP goals according to the family's schedule and priorities

What type of team would best meet the needs of Polly and her family? Why?

- A transdisciplinary team
- It would most effectively integrate services and communication across disciplines
- It would allow for equal input from all team members, especially Polly's family

What should the service team do to assist the family?

- The service team needs to work together to remove the stress Polly's family feels from the current lack of cooperation between providers. One way would be to use the consultation model to deliver services which would reduce the number of people in and out of their home.

REFERENCES

Bailey, D. (1984). A triaxial model of the interdisciplinary team and group process. Exceptional Children, 51(1), 17-25.

Bailey, D. (1989a). Case management in early intervention. Journal of Early Intervention, 13(120-134).

Bailey, D. (1989b). Issues and directions in preparing professionals to work with young handicapped children and their families. In J. Gallagher, P. Trohanis, & R. Clifford (Eds.), Policy implementation and P.L. 99-457: Planning for young children with special needs (pp. 97-132). Baltimore, MD: Paul H. Brookes Publishing Co.

Dyer, W. (1977). Team building: Issues and alternatives. Reading, MA: Addison-Wesley.

Hanson, J., & Lynch, E. (1989). Early intervention: Implementing child and family services for infants and toddlers who are at-risk or disabled. Austin, TX: PRO-ED.

Hutchinson, D. (1978). The transdisciplinary approach. In J. Curry & K. Peppe (Eds.), Mental retardation: Nursing approaches to care (pp. 65-74). St. Louis, MO: Mosby Co.

Maddux, R. B. (1988). Team building: An exercise in leadership. Los Altos, CA: Crisp Publications.

McCollum, J., & Hughes, M. (1988). Staffing patterns and team models in infancy programs. In J. Jordon, J. Gallagher, P. Hutinger, & M. Karnes (Eds.), Early childhood special education: Birth to three (pp. 129-146). Reston, VA: The Council for Exceptional Children.

McCollum, J., & McCarten, K. (1988). Research in teacher education: Issues and future direction for early childhood special education. In S. Odom & M. Karnes (Eds.), Early intervention for infants and children with handicaps: An empirical base (pp. 269-286). Baltimore, MD: Paul H. Brookes Publishing Co.

McCollum, J., & Thorp, E. (1988). Training to infant specialists: A look at the future. Infants and Young Children, 1(2), 55-65.

McCormick, L., & Goldman, R. (1979). The transdisciplinary model: Implications for service delivery and personnel preparation for the severely and profoundly handicapped. AAESPH Review, 4, 152-162.

McGonigel, M. (1988). Guidelines for family-centered research. Washington, DC: Association for the Care of Children's Health.

McGonigel, M., & Garland, C. (1988). The individualized family service plan and the early intervention team: Team and family issues and recommended practices. Infants and Young Children, 1(1), 10-21.

Orelove, F., & Sobsey, M. (1991). Educating children with multiple disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Prentice, R. R., & Spencer, P. E. (1986). Project Bridge: Decision-making for early services: A team approach. Illinois: American Academy of Pediatrics.

Rainforth, B., York, J., & Macdonald, C. (1992). Collaborative teams for students with severe disabilities: Integrating therapy and educational services. Baltimore, MD: Brookes Publishing Co.

Raver, S. A. (1991). Strategies for teaching at-risk and handicapped infants and toddlers. New York: Macmillan Publishing Company.

Shonk, J. H. (1982). Working in teams: A practical manual for improving work groups. New York: AMACOM.

Starcevich, M., & Stowell, S. (1990). Team effectiveness questionnaire. In M. Starcevich & S. Stowell (Eds.), Teamwork: We have met the enemy and they are us Bartlesville, OK: The Center for Management and Organization Effectiveness.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Team Process Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

COLLABORATIVE CONSULTATION

Recognize that others are experts in their fields and that everyone can benefit from sharing information.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe how collaborative consultation benefits children with disabilities.**
- **Describe and apply the principles of successful collaborative consultation.**

Consultation is an important part of early intervention and special education services. Federal legislation (Individuals with Disabilities Education Act) recognizes that no one agency or service provider has all the knowledge and skills necessary to meet the diverse needs of children with disabilities and their families. Thus, professionals must coordinate and collaborate at the local, state, and federal levels (Trohanis, 1989). This coordination and collaboration require a commitment from service providers within agencies to jointly plan, implement, and evaluate programs. In order to do this, however, they will need to communicate with one another, share their expertise and skills, solve problems together and jointly make decisions that will result in exemplary service delivery to the child in need.

Models of Consultation

Many models for consultation have been used to provide services to children with disabilities (File & Kontos, 1992); generally speaking, consultation is the giving and taking of information between people for the purposes of:

- identifying and resolving a need, issue, or problem; and
- improving the consultee's understanding of, and ability to respond effectively to, similar problems in the future (Gutkin & Curtis, 1982)

Consultation, then involves at least two people who come together to resolve a need, issue or problem; one of these people may also be involved in different consultations with various staff members. What is most important, however, is the relationship between the two key individuals in the consultation. When the consultation concerns providing services to a child with a disability, the child becomes the third key person.

Consultation can be used to provide a child with a disability with two types of services: direct and indirect (Idol, 1993). The consultant's **direct services** may encompass the assessment of, and instruction in, a child's deficit area (Idol, Paolucci-Whitcomb, & Nevin, 1986). The consultant can also provide **indirect services**, such as assistance to teacher who has a child with disabilities in his or her classroom, as well as assistance to the parents of this child (Idol, 1993). Clearly, a child with disabilities will require both types of consultation.

Current research on consultation strategies has focused particularly on strategies used in problemsolving (Tindal, Shinn, & Rodden-Nord, 1990). Researchers have suggested that both people involved in a consultation (the consultant and the consultee) prefer a collaborative model (Babcock & Pryzwansky, 1983; Pryzwansky & White, 1983; Wenger, 1979) rather than an expert model. The **collaborative model** (derived from Tharp and Werzel, 1969) is "an interactive process which enables people with diverse expertise to generate creative solutions to mutually defined problems." The major outcome of collaborative consultation is to provide comprehensive and effective services within the most appropriate context to the child with special needs (Idol, et al., 1986, p. 1).

COMPETENCIES AND PRINCIPLES

Collaborative consultation requires many interpersonal competencies that cross disciplinary boundaries; among these competencies are written and oral communication skills; such personal qualities as the ability to be caring, respectful, empathic, congruent, and open; and collaborative problemsolving skills (West & Cannon, 1988). The last, in particular, is crucial to developing a relationship of parity between the consultant and the consultee.

A number of principles contribute to the success of collaborative consultation across professionals from different disciplines (Idol et al., 1986); including:

- **Mutual ownership of the process.**

  It is important that both consultant and consultee together identify the need, issue, and problem. They should both accept responsibility for, or ownership of, the consulting process and its subsequent outcome. It is important that both people respect, recognize, and appreciate each other's expertise.

- **Recognition of individual differences in the change process.**

  The consultant and consultee should both be aware of the change process and the developmental stages of concern for change (Hall & Loucks, 1978). It is important that both recognize that people embrace change differently, at different rates and at different emotional levels.

- **Use of reinforcement principles and practices to improve skills, knowledge and attitudes.**

  When both consultant and consultee use effective teaching skills with each other and the child with disabilities, everyone benefits.

- **Use of data-based decisionmaking.**

  Collaborative consultation requires adopting a model of evaluation to measure the functional outcome of the intervention for the child and/or the family. Both the consultee and the consultant must continuously assess their effect on the childs identified need or problem in order to evaluate the effectiveness of their collaboration.

Recent research has suggested that consultation is likely to become an increasingly prominent method of service delivery for the child with special health care needs and disabilities (File & Kontos, 1992), but one cannot advocate collaborative consultation for service delivery by professionals from different disciplines without concern. This concern is especially relevant when working with staff from different agencies who may have different philosophies of service, financial resources, and time constraints (Johnson & Pugach, 1991; Johnson, Pugach, & Hammitte, 1988). For example, staff from one agency or discipline may perceive themselves to be more highly skilled than those from another agency (Carter, 1989; Pugach & Johnson, 1989); this can happen in a collaboration between a physician and a special educator or related service provider, each of whom is skilled in his or her own area. It is important that the staff involved acknowledge any such existing barriers before beginning their collaboration. All staff members must demonstrate mutual respect, as each will benefit from the other's expertise. This is the very core of a collaborative consultation relationship.

FAMILY STUDY

Jeffrey is five years old and lives at home with his mother, father, and seven-year-old sister. Jeffrey was born prematurely at a tertiary care hospital, where he remained hospitalized for two months after birth. Among Jeffrey's medical and developmental concerns are:

- Respiratory problems during the first weeks of life
- Upon arrival home, he appeared not to be alert or active; his parents were concerned about his development
- He sat up at 8 months and walked at 15 months
- His visual-perceptual skills appear normal. He could put together simple puzzles and build intricate block towers at two.
- At two he had no verbal language and could not consistently follow a one-step direction. He showed no interest in playing with other children and barely acknowledged his parents and sister
- He would not allow anyone to hold him and engaged in ritualistic behaviors such as, rocking and playing with string. He became extremely upset and often tantrums if he was placed in a new situation or if people tried to share materials he was using

At age 2 1/2, Jeffrey's family pediatrician referred the family to the local early intervention program for an evaluation and a determination of his eligibility for early intervention services; the assessment and evaluation determined that Jeffrey was indeed, eligible for services. Jeffrey's family then worked collaboratively with the early intervention program to develop an educational plan to meet Jeffrey's needs. Both Jeffrey's family and the program were committed to inclusive education (learning in natural environments with typical peers). Jeffrey received special education and related services five mornings a week in the school district's preschool program. These services were provided by a special education teacher, a full-time aide to help in his educational program, speech and occupational therapists who came three times a week, and a psychologist who consulted with the team to develop behavioral strategies.

This team of professionals worked with Jeffrey for two years. During that time Jeffrey continued to have great trouble with transitions among different activities within the normal routines of the day. For example, when freeplay ended, Jeffrey had great difficulty putting away toys in preparation for storytime: he screamed, threw things, cried and ran about the room. Jeffrey seemed to trust both the adults and his peers in preschool, especially his preschool teacher, his aide, and a particular classmate. The team began to work collaboratively on some behavior modification techniques to be used both in school and at home, to help Jeffrey improve his abilities to make transitions, to communicate, and behave appropriately in social situations.

To assist Jeffrey in communicating, the speech therapist created a communication program, through which the therapist determined that Jeffrey, at age 4 1/2, could read and spell words. The speech therapist therefore suggested "facilitated communication" to the team. Facilitated communication assumes competence on the part of the child. The facilitator holds the child's hand (usually at the wrist to provide resistance) as the child points to letters on a board to spell out words. Families and professionals who use this method typically receive some brief training.

Jeffrey's speech therapist and his mother went for training and in turn trained the rest of the team.

Jeffrey is now five and the school district has agreed to place him in a regular kindergarten. In this school system, Jeffrey's educational team from preschool did not follow him to kindergarten. He started school instead with an entirely new team including the classroom teacher, a special education consultant, a speech therapist, an occupational therapist, psychologist, and a full-time aide.

Jeffrey seemed to lose many of the gains he had made in preschool. He began to have great trouble transitioning, both within the classroom and outside to different specials such as art, gym, and library: Jeffrey yelled, screamed and threw tantrums. His family requested that the team use some of the behavioral strategies developed for Jeffrey in preschool. The school psychologist, however, thought that Jeffrey was beyond behavioral strategies and recommended drug therapy to help Jeffrey control his behavior; the psychologist repeatedly alluded to Jeffrey as out of control and a danger to himself and other children, and the kindergarten teacher began to agree. The special education teacher suggested that the team work consistently on some behavioral interventions, and give them time. The family was devastated by Jeffrey's situation and the school psychologist's recommendation. They did not want their son on drugs because they had heard horror stories from other families; they also perceived that because everything was new in their son's life he would need time before he could begin to trust people again. The school principal decided to ask an outside consultant to help resolve this issue. You are the physician who is to meet with this team and address the issue of medication versus behavioral strategies.

DISCUSSION

As Jeffrey's physician, how will you facilitate this process?

How will you elicit information to determine the problem?

What are some of the factors that contributed to this problem?

How would you define the problem?

What are some of the possible solutions?

How will you facilitate collaborative decisionmaking in the group?

What is your intervention strategy?

How will you monitor this strategy?

What skills do you need to implement this collaborative consultation process?

RESOLVE

The physician agreed to consult with Jeffrey's team, which included the special education consultant, the full-time aide, the kindergarten teacher, his mother and father, the speech therapist, the school psychologist, the occupational therapist, and the school principal. Before the meeting, the physician arranged to observe Jeffrey during a kindergarten session: he saw Jeffrey exhibit many behaviors that interfered with his ability to learn and function in the classroom. The physician also saw the negative effect of these behaviors on Jeffrey's classmates, and the team's inconsistency in dealing with Jeffrey's poor behaviors during their scheduled therapy times in the classroom.

At the meeting, Jeffrey's physician asked the team to discuss the current problems. His goal, as consultant, was to help the team define the problem clearly and objectively, which requires gathering information about the problem and its circumstances. The physician listened a great deal and asked questions aimed at more clearly defining the problem, which had been called "out-of-control behavior." Everyone agreed that Jeffrey's behavior had been disrupting classroom routines, his learning, and the other students. Everyone also agreed that prior to kindergarten, Jeffrey's behavior had become very manageable through consistent behavioral intervention provided at the preschool. The physician's next step was to help the team diagnose, as accurately as possible, the causes for the problem. He asked them to think about why Jeffrey's behavior had become out-of-control, and helped the team to list some reasons for Jeffrey's drastic changes in behavior. The team decided the primary reason was the lack of transition planning and collaboration between the preschool team and the current school team; other reasons included Jeffrey's having to adjust to all the new staff, and the lack of consistency within the program or with intervention strategies. The speech therapist mentioned that Jeffrey had previously used facilitated communication, and that no one on the current team understood it. Once the group agreed on possible causes for Jeffrey's behavior, the physician moved on to the next step in the collaborative consultation process: helping the team formulate strategies that would allow Jeffrey and the team to more effectively manage his out-of-control behavior. The physician encouraged the group to brainstorm strategies based on their "diagnosis" list.

Once the team listed possible intervention strategies, the physician's role as consultant was to help them decide which intervention strategies to pursue. In this part of the consultation process the consultant sometimes uses constructive confrontation if team members put up barriers to the decisionmaking process. In this case, the school psychologist was adamant about drug therapy, and the physician was comfortable in confronting this view. He was able to explain that although drug therapy was indeed an option, it was one of the most restrictive and least desirable for both the child and his family.

The physician facilitated the team members to discuss the benefits for each strategy, identify resources needed to implement the different strategies, and explore the likelihood of success of specific strategies. Through a group decisionmaking process, the current school team decided to consult with the preschool team for technical assistance and information on the behavior modification strategies that had worked for Jeffrey. The team also concluded that they needed to help Jeffrey with his communication skills. Their plan for Jeffrey consisted of the principal allowing members of the team release time to meet with the preschool team; the speech therapist providing facilitated-communication training and implementing a program for the team; and the psychologist agreeing to develop a behavior modification plan relevant to Jeffrey's current environment and helping staff implement that plan consistently, based on information and technical assistance from the preschool team. Finally, the physician helped the team establish an evaluation plan, with timelines to implement these strategies: in particular, they would assess the behavior modification strategies over the next two months to determine Jeffrey's progress. While the physician agreed with some of the team members' that drug therapy is a solution for some behavior problems, he was firm in believing that other, less-aversive strategies should be tried and evaluated before drug therapy could be considered. The team agreed not only to meet with the physician in two months to look at outcomes Jeffrey's progress but to maintain ongoing contact as needed.

DISCUSSION - ANSWERS

As Jeffrey's physician, how will you facilitate this process?

How will you elicit information to determine the problem?

- Consult with the professionals who work with Jeffrey at his school
- Visit Jeffrey at his kindergarten session
- Consult with Jeffrey's parents about their needs and perspective

What are some of the factors that contributed to this problem?

- Jeffrey's trouble with transitions
- The inability of Jeffrey's school team to use facilitated communication
- Jeffrey's lack of trust of new adults and peers
- The school team's not using the behavioral strategies that had worked in his preschool program
- Lack of transition planning between the preschool team and the kindergarten team

How would you define the problem?

- Lack of transition planning between the preschool team and the current school team.
- All new people in his life
- Jeffrey has trouble communicating because no one in the new setting understands facilitated communication
- Disagreement about the use of drug treatment for Jeffrey's behavior
- Lack of respect for the parent's thoughts and feelings

What are some of the possible solutions?

- Collaboration with Jeffrey's preschool team
- Train the current school team in facilitated communication

How will you facilitate collaborative decisionmaking in the group?

- Have the group agree on the problem clearly and objectively by open discussion.

What is your intervention strategy?

- Have the current school team meet with the preschool team for technical assistance and information (especially on behavior modification)
- Have the current school team trained in facilitated communication

How will you monitor this strategy?

- Maintain ongoing communication with the team
- Have the team meet at a predetermined time (two months) to discuss progress

What skills do you need to implement this collaborative consultation process?

- The ability to listen
- The ability to use conflict resolution skills when there is disagreement
- The desire by all parties to arrive at the best solution for the child
- The ability to help the team generate creative solutions
- Effective communication skills

REFERENCES

Babcock, N. L., & Pryzwansky, W. B. (1983). Models of consultation: Preferences of educational professionals at five stages of service. Journal of School Psychology, 21, 359-366.

Carter, J. F. (1989). The fact and fiction of consultation. Academic Therapy, 25, 231-242.

File, N., & Kontos, S. (1992). Indirect service delivery through consultation: Review and implications for early intervention. Journal of Early Intervention, 16(3), 221-233.

Gutkin, T. B., & Curtis, M. J. (1982). School-based consultation: Theory and techniques. In C. R. Reynolds & T. B. Gutkin (Eds.), The handbook of school psychology (pp. 796-828). New York: Wiley.

Idol, L. (1993). Special educator's consultation handbook (2nd ed.). Austin, TX: Pro-ed.

Idol, L., Paolucci-Whitcomb, P., & Nevin, A. (1986). Collaborative consultation. Austin, TX: PRO-ED.

Johnson, L. (1988). Program evaluation: The key to quality programming. In J. Jordon, J. Gallagher, P. Hutinger, & M. Karnes (Eds.), Early childhood special education: Birth to three (pp. 183-212). Reston, VA: The Council for Exceptional Children.

Johnson, L. J., & Pugach, M. C. (1991). Continuing the dialogue: Recognizing barriers to consultation and expanding our conceptualization of collaborative relationships. In W. Stainback & S. Stainback (Eds.), Controversial issues in special education Boston: Allyn & Bacon.

Johnson, L. J., Pugach, M. C., & Hammitte, D. J. (1988). Barriers to effective special education consultation. Remedial and Special Education, 9(6), 41-47.

Pryzwansky, W., & White, G. (1983). The influences of consultee characteristics on preferences for consultation approaches. Professional Psychology: Research and Practice, 14(4), 457-461.

Pugach, M. C., & Johnson, L. J. (1989). The challenge of implementing collaboration between general and special education. Exceptional Children, 56, 232-235.

Tharp, R., & Wetzel, R. (1969). Behavior modification in the natural environment. New York: Academic Press.

Tindal, G., Shinn, M. R., & Rodden-Nord, K. (1990). Contextually-based school consultation: Influential variables. Exceptional Children, 56, 324-336.

Trohanis, P. L. (1989). An introduction to P.L. 99-457 and the national policy agenda for service young children with special needs and their families. In J. J. Gallagher, P. L. Trohanis, & R. M. Clifford (Eds.), Policy implementation and P.L. 99-457 Baltimore, MD: Paul H. Brookes Publishing Co.

Wenger, R. D. (1979). Teacher response to collaborative consultation. Psychology in the Schools, 16, 127-131.

West, J. F., & Cannon, G. S. (1988). Essential collaborative consultation competencies for regular and special educators. Journal of Learning Disabilities, 21, 56-63.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Collaborative Consultation Date ____________________

Please rate the following statements:

	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.