

Special Education



A module designed to introduce primary health care providers to early intervention and special education services delivery systems.

*Developed by:
University of Connecticut
A.J. Pappanikou Center for Developmental Disabilities*

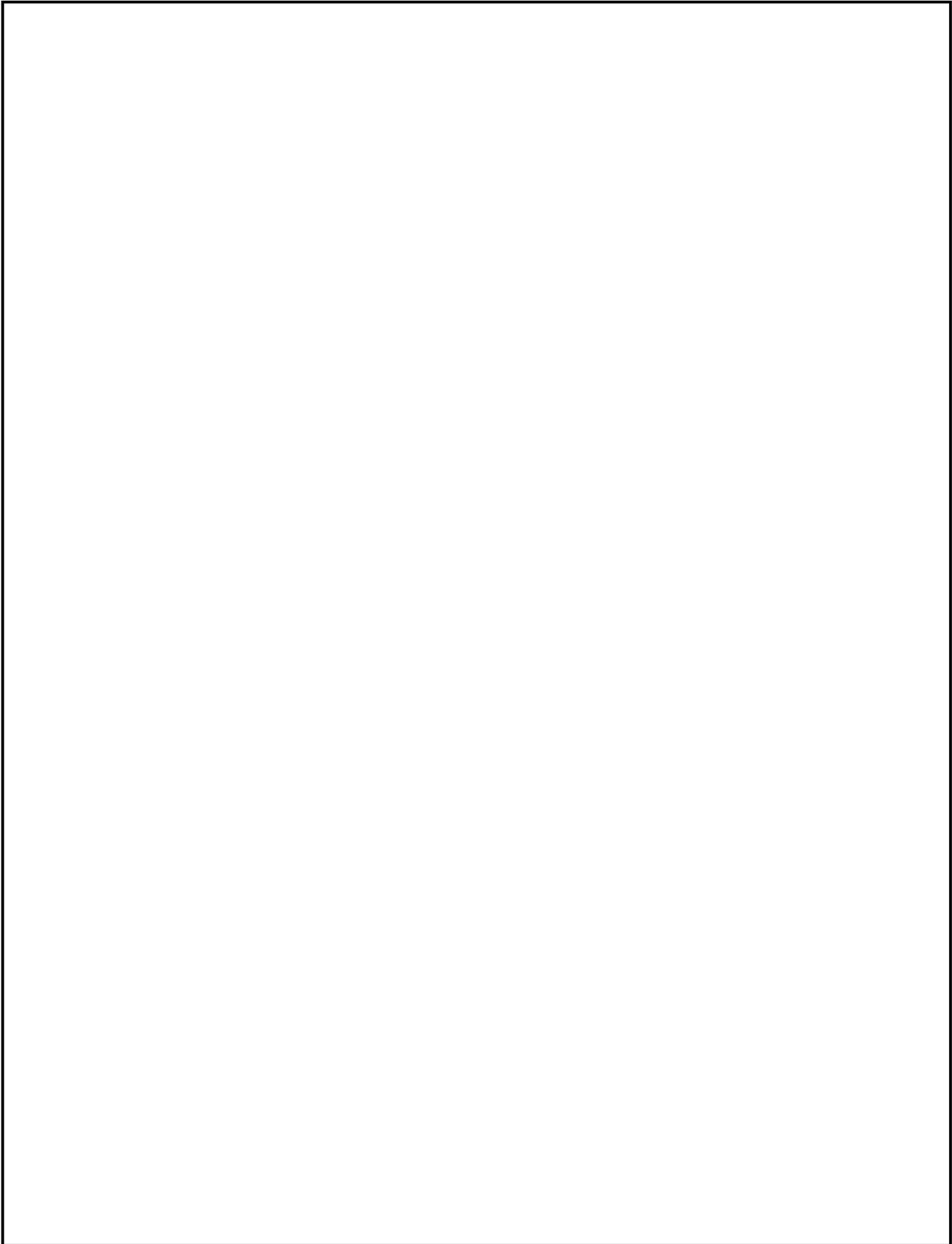


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INTRODUCTION

The purpose of this module is to introduce you to special education and the role of public schools in the provision of services to children, adolescents, and young adults with disabilities and/or special health care needs. Legislation affecting special education will be discussed, as well as legal issues related to the provision of health and medical services in the schools. The components of the Individualized Education Plan (IEP) will be presented with special attention devoted to issues surrounding inclusion in regular classrooms.

ORGANIZATION OF MODULE

The Special Education module is divided into four components. The first is a didactic component which covers special education law, the IEP, the types of health and medical services provided by public schools, and issues related to inclusion and least restrictive environments. The second component involves visiting a public school and observing how special education services are provided for children with disabilities. The third component requires you to observe one of your own continuity clinic patients in an early intervention or special education setting. The fourth component involves a specialty clinic visit where you will gain further exposure to children with disabilities and their families in a clinical setting.

Summary of organization of module:

- ❖ One half day didactic
- ❖ One half day school visit
- ❖ One half day early intervention or school visit with child from continuity clinic (to be arranged by resident)
- ❖ One half day specialty clinic visit

OBJECTIVES

At the completion of the Special Education module, you will be able to:

1. Describe and explain Part B of the Individuals with Disabilities Education Act (IDEA) and its major components, including eligibility requirements.
2. List and explain the major components of an IEP.
3. Describe the process necessary to refer a child with developmental delays and/or special health care needs for special education services.
4. Describe the major premise of “least restrictive environment” as it relates to children receiving special education services.
5. Describe the steps necessary for successful transitions from early intervention, preschool, and school-age services.
6. Describe how court decisions have influenced health-related services in providing a free, appropriate public education to children with disabilities.
7. Understand the impact of Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA) on persons with disabilities.

COMPONENT ONE: INTRODUCTION TO SPECIAL EDUCATION

Location and Times:

These will be established by the project coordinator in conjunction with the chief residents. You will be notified by either the coordinator or a chief resident with as much advanced warning as possible.

Format:

Information will be presented through discussion, reading materials, and case studies. Videos are optional.

Resident's Responsibilities:

Please arrive on time and come prepared to participate in the conversation. It will be a more productive session if you have read the materials beforehand. Be prepared to critique the session afterwards.

REFERENCES

RELATED READINGS

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RELATED VIDEOTAPES

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(Available from The B.C. Association For Community Living, #300-30 E. 6th Avenue, Vancouver, B.C., Canada V5T 4P4)

Warger, Eavy & Associates with Hamilton Productions (Producer & Director).
(1996). Welcome to My Preschool! [Videotape]. (Available from NCIP,
c/o Judy Zorfass, Education Development Center, Inc., 55 Chapel Street,
Newton, MA 02158-1060)

SPECIAL EDUCATION HISTORICAL PERSPECTIVES

Over the course of this century, there has been a great paradigm shift in how children with disabilities are viewed and treated in terms of their education and roles in society. Well into the middle of this century, the prevailing view was that children with disabilities should be removed from regular society. Many children with disabilities, especially with mental retardation, were placed in institutions, attended special classes or schools, or were kept home and out of sight. The underlying assumption was that the children needed to be protected, and that their presence in the regular classrooms would be too disruptive, and even dangerous, for the other students.

By the 1950s, there began to be a shift in view about children with disabilities to one where the value and worth of every child was being recognized. Attitudes were also influenced by the civil rights movement, especially by the recognition that segregation of minority groups inevitably leads to unequal treatment. Attitudes about special education and the treatment of children with disabilities were profoundly influenced by the 1954 Supreme Court decision in *Brown v. the Board of Education*, 347 U.S. 483 (1954). This decision recognized that educating black children separately, even if done so in equal facilities, was inherently unequal because of the stigma attached to being educated separately and because of the deprivation of interaction with children of other backgrounds.

However, even by the early 1970s, most children with disabilities in the U.S. were being underserved or were not served at all by schools. Prior to the enactment in 1975 of the Education for All Handicapped Children Act (P.L. 94-142), there were approximately eight million children with disabilities in the U.S.; three million were not receiving appropriate programming in school, and one million were totally excluded from the educational system. At that time, special education programs were being criticized for the following problems: haphazard and inconsistent identification and placement of children, disproportionate numbers of African American, Latino, and other minority groups placed in special education classes, the discouragement of parental involvement, and lack of cooperation between regular and special educators.

Two landmark court decisions set the stage for major changes in educational programs for children with disabilities: *Pennsylvania Association for Retarded Children (PARC) v. Pennsylvania*, 334 F. Supp. 1257 (E.D.Pa. 1971) and *Mills v. D.C. Board of Education* in 1972, (348 F. Supp. 866 D.D.C. 1972). The district courts in these two cases ruled that states could not deny education to children with mental retardation and disabilities without due process. Congress finally addressed the issue of special education in 1975 with the Education for All Handicapped Children Act (P. L. 94-142), which in 1991 was amended and renamed the Individuals with Disabilities Education Act or IDEA (P. L. 102-119).

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, PART B (IDEA)

The Individuals with Disabilities Education Act or IDEA is the central component of the federal policies that guide the education of children with disabilities in this country. Part B of this act authorizes funding for special education. It is a federally mandated program that guarantees all children with disabilities, ages 3 to 21, a free, appropriate public education. It was the intent of Congress in enacting IDEA to include all children regardless of type or severity of disability. All states are required to follow this policy of zero rejection.

GOALS

The four fundamental goals of IDEA include:

- ❖ Free appropriate public education (FAPE).
- ❖ Protecting the rights of students and parents in securing FAPE.
- ❖ Assisting states and local educational agencies to provide for FAPE.
- ❖ Ensure the effectiveness of these efforts.

On June 4, 1997, President William J. Clinton signed into law the reauthorization of IDEA (P.L. 105-117). This reauthorization enhances the fundamental rights of students and substantially increases the right of parent participation.

In 1997, the reauthorization of IDEA reinforced the original purposes and included many others. Most notably, there were proposed specific solutions to attitudinal and capacity barriers. These solutions included strengthening parent roles and ensuring parent participation, ensuring students access to general curriculum, having high expectations for students, supporting high-quality professional development for personnel, coordinating IDEA with other school improvement efforts, and focusing resources on teaching and learning while reducing paperwork and requirements that do not assist in improving educational results.

IDEA 1997 continues the fundamental civil rights protections and preserves due process procedures. The reauthorization emphasizes the need for all involved parents, administrators, teachers, and governmental officials to collaborate to improve educational opportunities and ensure accountability and results.

KEY COMPONENTS

The key components that all states are required to follow under Part B of IDEA include:

- ❖ Referral process
- ❖ Eligibility
- ❖ Services and related services
- ❖ Placement and least restrictive environment
- ❖ Nondiscriminatory assessment
- ❖ IEP
- ❖ Transitions
- ❖ Due process and parent participation

Referral process

Local school districts handle referrals for special education. Each district must follow the same general process, however, there may be variation among the districts in a state as to the specific policies they follow. If a parent or physician feels that a child may require special education services, they should contact the local public school district's office of special services verbally and in writing. This will initiate the referral and evaluation process. Before formal evaluation occurs, the classroom teacher may try prereferral interventions. This serves as a way to problem solve to identify factors which may be impacting a child's school performance and develop strategies for alleviating these problems without having to place a child in special education. This is also a way to obtain more information about the child that can be useful when writing an IEP if the child does indeed require special education services. If the prereferral intervention strategies are successful, the process ends, although the child's progress will continue to be monitored and additional modifications in the intervention may be made as needed. If the prereferral strategies are not effective, the team begins the formal evaluation process.

Each district has a special services team consisting of teachers, psychologists, social workers, counselors, therapists, and administrators which coordinate the process of identification, planning of services, and related services. This results in the written IEP, which then results in placement in the least restrictive environment.

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. Evaluation occurs to determine eligibility for services. Reevaluation occurs under three circumstances:

- ❖ A reevaluation must be done at least every three years.
- ❖ A reevaluation must occur in less than three years if there has been a dramatic improvement or deterioration in the student's disability.
- ❖ A reevaluation must occur if a parent or teacher requests it.

Eligibility

Eligible disabilities under IDEA for ages 3-21 include:

- | | | |
|--|---------------------------------|---|
| ❖ Mental retardation | ❖ Multiple disabilities | ❖ Autism |
| ❖ Hearing impairments including deafness | ❖ Serious emotional disturbance | ❖ Other health impairment |
| ❖ Speech and language impairments | ❖ Orthopedic impairments | ❖ Specific learning disabilities |
| ❖ Visual impairments including blindness | ❖ Traumatic brain injury | ❖ Developmental delay (for children ages 3-5) |
| ❖ Neurological impairment (CT addition) | | |

IDEA defines children with disabilities as those who have one or more of these specific conditions and who, because of their disability, need special education and related services (i.e., specifically designed instruction) to meet their educational needs.

Individualized Education Plan or IEP

The IEP is a planning document that serves as a vehicle between parents and school personnel to jointly decide upon the student's needs, the services which will be provided to meet those needs, and what the anticipated outcomes may be. It sets forth in writing a commitment of resources necessary to enable a student to receive needed special education and related services. The IEP also serves as an evaluation device for use in determining the extent of the student's progress toward meeting the projected outcomes. Lastly, it is a legal document that may be used by authorized monitoring personnel from each governmental level to determine whether a student is actually receiving the free, appropriate public education agreed to by the parents and the school.

This document must include the following components:

- ❖ A statement of the student's present levels of educational performance, including how the student's disability affects their involvement and progress in the general curriculum.
- ❖ A statement of measurable annual goals, including benchmarks or short-term objectives related to (a) meeting the student's needs that result from his or her disability to enable the student to be involved in and progress in the general curriculum and (b) meeting the student's other educational needs.

- ❖ A statement of (a) the specific special education and related services and (b) supplementary aids and services to be provided.
- ❖ An explanation of the extent, if any, to which the child will not participate with nondisabled children in general education and other general curriculum activities.
- ❖ A statement of any individual modifications in the administration of state and districtwide assessments of student achievement.
- ❖ The projected dates for beginning the listed services and modifications and the anticipated frequency, location, and duration of those services and modifications.
- ❖ IDEA states that at age 16 a statement of needed transition services for the student including, where appropriate, a statement of interagency responsibilities or any needed linkages must be included. CT transition law begins services on a student's 15th birthday.
- ❖ Beginning at least one year before the student reaches the age of majority (age 18), a statement that the student has been informed of the rights under IDEA, if any, that will transfer to them upon reaching the age of majority.
- ❖ A statement of (a) how the student's progress toward the annual goals will be measured and (b) how the student's parents will be informed regularly (at least as often as parents are informed of their nondisabled children's progress).

This document should be developed by a team composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others (such as a physician) invited by the parents to the school. The 1997 IDEA amendments require a general education teacher to be a member of the IEP team to assist the team in the development and determination of appropriate interventions, behavioral support, and supplementary aids. An IEP for a student, along with a blank form, is located in Appendix A. In Connecticut, this team is called a planning and placement team (PPT). In other states it may be referred to simply as an IEP team.

Services and related services

Special education is defined as specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child in accordance with the IEP. Related services are part of the free, appropriate public education that states must provide to all children with disabilities in order to be eligible for funding under IDEA. A child receives related services that he or she needs in order to benefit from special education. For example, assistive technology is a related service and under the 1997 IDEA amendments the IEP team must address whether a child requires assistive devices or services. The need must be considered when developing the IEP, whether or not a device or service is required. Devices can range from low tech, such as laminated pictures for communication, Velcro, or specialized drinking cups, to high tech, such as computers or wheelchairs. An 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 used to increase, maintain, or improve the functional capabilities of children with disabilities.

An assistive technology service means any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device. The physician can contribute to the IEP team's assessment in person, by phone, or by letter to give his or her opinion on medical needs that may necessitate assistive services or devices.

In June of 1997, Public Act 97-100, The Assistive Technology Lemon Law, was enacted in Connecticut to provide consumers with protection regarding warranty and lease guarantees on non-conforming devices needing replacement or repairs. (Please see Appendix B for a list of assistive technology resources.)

The types of related services include:

- ❖ Assistive technology and related services
- ❖ Audiology
- ❖ Early identification and assessment of disabilities
- ❖ Transportation and related costs
- ❖ Psychological services
- ❖ Parent counseling and training
- ❖ Physical and occupational therapy
- ❖ Recreation (including therapeutic recreation)
- ❖ Counseling services (including rehabilitative counseling)
- ❖ Occupational therapy
- ❖ Medical services for diagnostic or evaluative purposes
- ❖ School health service
- ❖ Social work
- ❖ Speech and language therapy
- ❖ Supplementary aids and services
- ❖ Orientation and mobility services

Appendix C contains an article from the American Academy of Pediatrics about the provision of related services.

Placement and least restrictive environment

IDEA requires that children receive special education services in the “least restrictive environment.” This means that to the maximum extent appropriate, schools must educate children who have disabilities in settings in which they have opportunities to meet, socialize, and interact with children without disabilities, while still appropriately meeting each child’s special needs through the use of supplemental aids, services, and supports. The following are some of the specific issues addressed under “least restrictive environment.”

- ❖ 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, self-contained special education classes, etc.) and supplementary services (adaptive physical education, speech and language, etc.).
- ❖ 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.

Inclusion reflects the philosophy that all people are equal and should be respected and valued. It is a process in which children and adults with disabilities have the opportunity to participate fully in all community activities offered to people who do not have disabilities. It allows people with and without disabilities to learn, work, and play side-by-side.

Successful inclusion requires commitment, collaboration, creativity, and persistence. The components needed for successful inclusion include:

- ❖ Commitment on the part of school administration. School administrators should express their commitment to the inclusion of all children in regular classrooms by communicating their support, providing teachers the necessary training and resources, and demonstrating their appreciation of the teachers' efforts.
- ❖ Commitment on the part of instructional staff. Although the level of commitment may vary, all instructional staff should be committed to the basic goal of including all children. An essential component of this process is obtaining input from the instructional staff and providing them the opportunity to participate fully in the planning and decision-making process.
- ❖ Commitment to develop ways to share expertise. The key is to develop a collaborative working relationship among the family, teachers,

administrators, and other professionals. Input from the child's physician or medical team can be extremely useful as well.

- ❖ Commitment to develop a process for transition and maintenance plans. Team members must continue to work together in a collaborative manner to monitor the progress of the child and make modifications as needed. It is also important to plan for transitions to the next grade, new schools, vocational programs, etc.
- ❖ Consultative support for the planning team. It is very helpful for the team to have access to consultative support as they develop an IEP and plan for the needs of the child. This person can be an educational specialist, school psychologist, or anyone who has expertise in meeting the educational needs of children with disabilities in an inclusive setting.

Transitions

Children experience transitions over time such as moving from Birth to Three to the school system, moving to the next grade and a new classroom each year, attending a new school for middle or high school, etc. Children receiving special education services may move between a regular classroom and a more restrictive setting. Children with special health care needs may fluctuate between receiving homebound services and attending school. All transitions require planning to prepare the child for the new settings.

Teachers and other support staff also need to be prepared to meet the needs of their new students. The key to successful transitions is a collaborative team effort. Following are the steps for successful transitions for children receiving special education services within inclusive settings:

- ❖ Identify the student's strengths and educational needs.
- ❖ Identify existing resources provided in the student's program.
- ❖ Describe the student's current educational program.
- ❖ Identify and analyze potential next placements.
- ❖ Select the next placement for the student.
- ❖ Develop a schedule of activities which detail needed adaptations, materials, and resources.
- ❖ Develop transition activities in order to prepare the student (e.g., visiting new school, meeting the teacher).
- ❖ Provide for the addition of resources or technical assistance to the student's program as needed.
- ❖ Provide for training of school staff and students without disabilities as needed.
- ❖ Provide for continued parental involvement.
- ❖ Monitor student progress and modify it as needed.

Planning for the transition from Part C of IDEA infant and toddler services to preschool services should begin at least 6 months before the child turns three. On the child's third birthday, the local public school becomes responsible for providing special education services for that child, if he or she is eligible under IDEA. Please see Appendix D for a comparison of preschool (Part B) and infant/toddler (Part C) programs of IDEA. At least 60 days before a child's third birthday, there should be a meeting with representatives from the early intervention team, local school district, and

the family to prepare for this transition. This should serve as an opportunity to exchange information about the child, including medical information.

Part B of IDEA defines transition services as a coordinated set of activities for a student designed within an outcome-oriented process that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

Transition services are required to be provided for adolescents receiving special education services so that they can prepare for the demands of adulthood. IDEA mandates that these services be included in a student's IEP no later than age 16. In Connecticut however, the Connecticut Transition Legislation (P.A. 87-324) states that the transition plan "shall be developed not later than at the annual review of the prescribed educational program next following such child's fifteenth birthday and shall be included as part of such prescribed educational program." It also states that transition services may be included prior to the child's fifteenth birthday where appropriate (please see Appendix E).

The coordinated set of activities must be based on the individual student's needs, taking into account the student's preferences and interests. These activities may include the following: instruction, community experiences, the development of employment and other post-school adult living objectives, and the acquisition of daily living skills and a functional vocational evaluation

(please see Appendix E for more information on the development of a transition plan). For example, one adolescent may need to focus on providing vocational training so that she can find employment after graduation. For another, it may entail developing functional skills, such as dressing oneself or learning how to acquire and use personal care assistant services so that they can live independently. Yet another may need to meet his transportation needs for going away to college. He may need to learn how to use public transportation or get his driver's license and acquire adaptive equipment for a vehicle. Any skill a particular student may need in order to achieve the activities listed in the transition plan is part of this process and therefore becomes an educational goal.

The transition plan must identify interagency responsibilities necessary to prepare the student to leave the school setting. It is ultimately the educational agencies responsibility to ensure that the needs are met, so if another named agency fails in their duties, the school must find an alternative method for meeting the goals. Examples of the agencies a school may turn to to help meet transitional goals are the Bureau of Rehabilitation Services (BRS), Department of Mental Retardation (DMR), Department of Mental Health Addiction Services (DMHAS), Department of Social Services, or various special service organizations such as independent living centers, United Cerebral Palsy Association, Easter Seals Rehabilitation Center, or supported employment agencies.

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 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) meeting and be 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 mediation and/or an impartial due process hearing conducted by a hearing officer, 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. Mediation and 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 not available.

CASE LAW AFFECTING HEALTH-RELATED SERVICES

Often children with special health care needs require health-related services to be able to attend school and thus receive special education services. Health services are only one of the many related services under IDEA that students are entitled to receive for a free, appropriate public education. Providing health services has been a controversial issue among local school districts, state educational agencies, parents, and advocates. Courts have addressed this issue of whether a particular service such as catheterization, nursing services, and mental health services are “medical services” or “related health services.” Related health services must be provided and paid for by the local education agency, medical services are not, with the exception of medical diagnosis and evaluation. Lower district courts and courts of appeal in various states have issued decisions divided on the subject.

In 1984 *Irving Independent School District v. Tatro* and in 1999 *Cedar Rapids School District v. Garret F. by Charlene F.*, the U.S. Supreme Court clarified the definition of a related health service. The court held in *Tatro* in a unanimous opinion that clean intermittent catheterization (CIC) is a related service that schools have to provide. The following is a summary of the case.

Irving Independent School District v. Tatro, 468 U. S. 883 (1984): Amber Tatro is an 8-year-old girl born with a condition known as spina bifida. As a result, she suffers from orthopedic and speech impairments and a neurogenic bladder, which prevents her from emptying her bladder voluntarily. Consequently, she must be catheterized every three or four hours to avoid injury to her kidneys. In

accordance with accepted medical practice, a procedure called clean intermittent catheterization (CIC), involving the insertion of a catheter into the urethra to drain the bladder, has been prescribed. The procedure is a simple one that may be performed in a few minutes by a layperson with less than an hour of training. Amber's parents, baby-sitter, and teenage brother are all qualified to administer CIC, and Amber soon will be able to perform this procedure herself.

In 1979 petitioner Irving Independent School District agreed to provide special education for Amber, who was then 3 ½ years old. In consultation with her parents, who are respondents here, petitioner developed an individualized education program for Amber under the requirements of the Education for all Handicapped Children Act of 1975. The individualized education program stated that Amber would attend early childhood development classes and receive special services such as physical and occupational therapy. That program, however, made no provision for school personnel to administer CIC.

Respondents unsuccessfully pursued administrative remedies to secure CIC services for Amber during school hours. In October 1979 respondents brought the present action in district court against petitioner, the State Board of Education, and others. They sought an injunction ordering petitioner to provide Amber with CIC and sought damages and attorney's fees.

The court decided that CIC is a related service that the school was obliged to provide for Amber. There were two main arguments for this decision. Firstly, they decided that CIC is a "supportive service ... required to assist a handicapped child to benefit from special education." Secondly, they

decided that CIC was a “school health service” and not a “medical service,” which the school is required to provide only for purposes of diagnosis or evaluation. They went on further to clarify the difference between these. School health services are services that can be provided by a qualified school nurse or other qualified person. Medical services are services that can only be provided by a licensed physician. The court also outlined several limitations. First, to be entitled to related services, a child must be handicapped so as to require special education. Second, only those services necessary to aid a handicapped child in benefiting from special education must be provided, regardless of how easily a school nurse or layperson could furnish them. Third, the regulations state that school nursing services must be provided only if they can be performed by a nurse or other qualified person, not if they must be performed by a physician.

Again in *Cedar Rapids Community School District v. Garret F. by Charlene F.* (1999), the U.S. Supreme Court followed the reasoning from *Tatro*. The following is a summary of the case.

Garret Frey is a high school student in Cedar Rapids, Iowa who was paralyzed from the neck down in a childhood accident. He uses a power wheelchair, has a tracheotomy, needs a ventilator, is catheterized daily, and requires monitoring of his equipment and health status 24 hours a day. Garret’s family (none of them medical professionals) cares for him at home. According to Supreme Court Justice John Paul Stevens, Garret is “a friendly, creative and intelligent young man.”

The Cedar Rapids school district said that Garret’s severe condition required “medical treatment” by a registered nurse during school hours, but that

schools were not obligated to pay for the care. The district gave the Freys two choices: 1) pay for a nurse at school or 2) have Garret tutored at home one hour a day. The Frey family believed that IDEA obligates school districts to pay for related school health services. Earlier federal court decisions also established that schools must pay for certain health-related services. Unable to reach a compromise, the Frey family resorted to a legal solution. Garret won at several court levels, finally reaching the Supreme Court.

When he started school, Garret was assisted by a specially trained attendant. Later, at the insistence of the Cedar Rapids school district, a licensed practical nurse (LPN) helped Garret. The LPN was paid for through his family's insurance policy until its cap was reached. Garret is now ineligible for private insurance. Because they believed that Garret had a right to attend school with in-school health supports paid by the district, the Frey family filed their suit.

On March 3, 1999, in their 7-2 ruling in the *Garret F.* case, the U.S. Supreme Court said that IDEA requires schools to provide health supports for students who need them, as long as that care is not medical in nature and must be performed by doctors. The ruling states that, "... the district must fund such related services to help guarantee that students like Garret are integrated into the public school."

When the Supreme Court looked at the definition of "related services" in IDEA, it noted that the disputed services were incorporated within the definition of related services. These disputed services were considered support services because they were necessary for the student to attend school. Further, in *Tatro*, it held that medical services are those services that must be performed by a physician.

When applying the reasoning of the Supreme Court in *Tatro* to *Cedar Rapids*, we see why the local district was required to provide the requested service: because it did not need to be provided by a physician. Although the local district claimed that this service would be a financial undue burden, it was deemed inconsistent with the purposes of IDEA.

The *Garret F.* decision means that all students, no matter their health condition (The Zero Reject Principle), have a right to attend school with necessary services paid by the school district. School districts, family members, pediatric leaders, and state health officials can sit down together to find creative ways to ensure that students like Garret are able to attend school.

Physicians are a valuable asset as they understand the technological supports associated with caring for children with complex medical conditions. They are also powerful advocates for the family as they try to access needed supplies and services.

The child's primary health care provider is the most appropriate source for medical recommendations to follow while the child receives special education services. He or she is in the best position to evaluate how the child's medical needs will impact special education services, the child, and the family.

ADDITIONAL LEGISLATION AFFECTING THE RIGHTS OF PERSONS WITH DISABILITIES

SECTION 504 OF THE REHABILITATION ACT OF 1973

Section 504 of the Rehabilitation Act is civil rights legislation that prohibits discrimination against people with disabilities. It requires that any program or activity that receives federal assistance must provide equal and accessible transportation, architecture, educational programs, and nonacademic services for children and adults with disabilities. If services for people with disabilities are separate, the quality of the services cannot be substantially different.

Section 504 defines a person with a disability as any person who:

- ❖ Has a physical or mental impairment which substantially limits one or more of such person's major life activities.
- ❖ Has a record of such an impairment (e.g., cancer which is not in remission).
- ❖ Is regarded as having such an impairment (e.g., disfiguring burns).

Major life activities include:

- | | | |
|----------------------|------------|---------------------------|
| ❖ Caring for oneself | ❖ Seeing | ❖ Performing manual tasks |
| ❖ Breathing | ❖ Hearing | ❖ Learning |
| ❖ Walking | ❖ Speaking | ❖ Working |

(Note: Recent court decisions also include sleeping, concentrating, and reproduction as major life activities.)

Students who do not qualify for services under IDEA may be eligible to receive services and protection under Section 504. The student must be determined, as a result of an evaluation, to have a physical or mental impairment which substantially limits one or more of the student's major life activities. Unlike IDEA, there is no list of diagnoses that qualify someone for Section 504 services. Qualification is based solely on limitations to major life activities rather than specific diagnoses.

For example, a student with HIV who exhibits no major symptoms or needs for accommodation may qualify for protection against discrimination or exclusion from activities or services under Section 504, but until they develop substantial needs for modifications, they would not qualify for coverage under IDEA.

“Physical or mental impairment” means (a) any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory, speech organs, cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin, and endocrine or (b) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities (please see Appendix G for more information on the requirements under Section 504).

AMERICANS WITH DISABILITIES ACT OF 1990

The Americans with Disabilities Act (ADA) was based to a large extent on Section 504 and uses the same definition of disability as outlined above. Its

coverage is broader, however, and includes five titles which address specific concerns or groups of organizations:

- ❖ Title I: Employment of people with disabilities
- ❖ Title II: State and local governments (including public transportation)
- ❖ Title III: Public accommodations (including retail establishments, museums, places of lodging, restaurants, theatres, stadiums, commercial service establishments, places of recreation, schools, social service establishments, transportation facilities)
- ❖ Title IV: Telecommunications (telephone relay services)
- ❖ Title V: Miscellaneous (including construction, state immunity, wilderness areas, transvestites, illegal use of drugs, congressional inclusion)

The ADA clearly states that all Americans, including those with disabilities, are entitled to the same rights and privileges. It ensures that individuals with disabilities are assured equality of opportunity, full participation, independent living, and economic self-sufficiency. It also extends protection to those associated with someone who has a disability (i.e., parent, child, family member). The only groups exempt from ADA compliance are Indian tribes (on reservation land), religious institutions, private membership clubs, and corporations wholly owned by the government of the United States, such as military branches. In addition, private residences are not covered by the ADA because they are included in the Fair Housing Amendment Act. In the same vein, air carriers are addressed in the Air Carriers Access Act of 1986, rather than the ADA (see Appendix H for more information on these two acts).

All public accommodations, including schools and early childhood facilities (unless operated by religious institutions), are required to comply with ADA. For example, no public school or child care program may exclude a child with a disability, and accommodations must be made, if necessary, so that the child may fully participate in the program. This also includes private child care and preschool programs.

Many organizations exist as resources to understand ADA and its implications for businesses, organizations, schools, and individuals with disabilities. Some examples of these are independent living centers, state Offices of Protection and Advocacy for Persons with Disabilities, U.S. Department of Justice, U.S. Access Board, and Adaptive Environments (see Appendix H for a list of resources).

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 15 months of age. The concerns were as follows:

- ❖ Trevor has cerebral palsy; he is, however, ambulatory.
- ❖ He has a very narrow airway.
- ❖ He has vision difficulties, 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 the fourth grade level, which is appropriate for his age. This is the first year that Trevor has been in the self-contained classroom. The Planning and Placement Team or PPT (Trevor’s parents and appropriate school personnel) decided that this was the most appropriate program for him. This decision was based on the following concerns:

- ❖ Trevor often required that instructions for assignments be repeated.
- ❖ Trevor’s behavior in the mainstream or “regular ed” classroom was often disruptive, and the teacher had a difficult time getting him and the rest of the class back on task.
- ❖ Class sizes were increasing, and the teacher would not be able to give Trevor the more “individualized” instruction he might need.

- ❖ The school staff judged that Trevor’s learning disability and his physical disability dictated a more “restrictive” educational setting.

Trevor’s IEP was developed by the PPT and he was placed in the self-contained classroom. After an initial period in this special education environment, Trevor’s parents had reasons to reconsider this placement. Trevor’s behavior had worsened since he had been in the self-contained program and his pediatrician was concerned that he was acting out his anger and unhappiness about being in this class. Additionally, Trevor was attending a different school than other children in the neighborhood, including his sister Lisa. This made child care arrangements even more difficult for his parents to manage. Trevor’s parents requested a PPT meeting to revise his IEP and to address the following options:

- ❖ Placing Trevor in a regular education setting with modifications to the curriculum or school day to assist him in learning.
- ❖ The provision of appropriate special education and related service supports.
- ❖ Completion of a comprehensive evaluation to assess Trevor’s current functioning levels and educational needs.
- ❖ Encouraging Trevor to have appropriate interactions with his peers with the goal of establishing positive relationships.

For the PPT meeting, the neurologist sent a letter supporting Trevor’s placement in a regular education setting with modifications and support services. His parents brought an advocate, a distant cousin of his mother’s who

was a special education teacher. The PPT meeting lasted three hours. However, the participants could not reach an agreement about the most appropriate program for Trevor. To resolve this dispute, Trevor's parents filed the required forms with the Department of Education to begin due process.

FAMILY STUDY--REVISITED

DISCUSSION QUESTIONS

As Trevor's primary pediatrician, evaluate the following:

According to the IDEA and ADA, what should your role be in addressing Trevor's educational needs?

As Trevor's primary physician, how can you assist the family through the process of changing Trevor's IEP?

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

Discussion Question Answers

- ❖ According to the IDEA and ADA, what should your role be in addressing Trevor's educational needs?
 - ◆ Collaborate with members of the IEP team 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 and related service needs has been completed.
 - ◆ Determine the need for any assistive technology services or devices.

- ❖ As Trevor's primary physician, how can you assist the family through the process of changing Trevor's IEP?
 - ◆ Support the family regarding Trevor's medical and emotional issues.
 - ◆ Attend the PPT meeting in person, via telephone, or some other media, to provide the team with your concerns and support the family.
 - ◆ Explain Trevor's medical conditions and emotional issues.

- ❖ If Trevor were two years old, how might this process be different under Part C of IDEA?
 - ◆ Under Part C an Individualized Family Service Plan (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.

Resolution

Trevor's parents filed for a due process hearing 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 as an intermediate step in the process. 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 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 session. They also asked Trevor's

primary pediatrician to attend. Both physicians agreed to come because they thought it was important to establish a mechanism for ongoing communication with school personnel about 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 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 of how Trevor reacted to certain stresses and conditions. He noted that Trevor expressed that he felt different and angry at being placed in the self-contained fourth grade class, instead of a 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 management 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 also wanted to work collaboratively with school district personnel. His parents further agreed that it was important to let Trevor speak at the meeting and for school district officials to hear his concerns.

Trevor's parents also asked his third grade teacher to attend the mediation. She had told Trevor's parents during the PPT meeting that she would have recommended regular fourth grade if appropriate 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 mediators that when Trevor had previously been placed in regular education, he did not have supplementary supports, a curriculum plan, or a behavior management plan.

The family asked the advocate to attend as well. Trevor's parents were comfortable with the team 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 personnel if they agreed to place Trevor back in regular education. The family went to mediation with a positive attitude. However, if mediation did not work, they were prepared to pursue this issue at a due process hearing, which is their right under the law.

Since their last PPT meeting, the advocate had told Trevor's parents of a ruling in U.S. 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. This depends upon the needs of the child and the class, as determined by the teachers and team involved.

The court ruled that any IEP that recommends self-contained special education classes with no meaningful opportunities for integrating the child with non-disabled children violates 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, a curriculum plan, or a behavior management plan. Trevor's parents felt that their concerns were supported; this is exactly what they had been trying to explain to school district officials in terms of Trevor's placement in regular education.

COMPONENT TWO: SPECIAL EDUCATION PROGRAM VISIT ELEMENTARY, MIDDLE, OR HIGH SCHOOL

Location and Times:

You will visit a public school and observe a child who receives special education services in an integrated inclusive setting. The visit will last two to three hours and will be scheduled based on the resident block schedule.

Format:

Observe the classroom to see what a typical day is like for the children. Talk with the regular teacher, special education teacher, and other related support staff. You may be accompanied to the school by a staff member from the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities. Please refer to *Guidelines for Special Education Program Visit*.

Resident's Responsibilities:

You should provide your own transportation to the school. Staff should be interviewed using the *Guidelines for Special Education Program Visit: Elementary, Middle, or High School*. You should complete the *Resident Self-Evaluation: Special Education Program Visit*. A staff member at the school should complete the *Performance Rating by Preceptor*.

GUIDELINES FOR SPECIAL EDUCATION PROGRAM VISIT: ELEMENTARY, MIDDLE, OR HIGH SCHOOL

Elementary School

Purpose:

- ❖ To gain firsthand knowledge of how special education services may be provided for children with disabilities at the elementary school level.
- ❖ To consider how children with disabilities can be included in regular classrooms with appropriate supports.
- ❖ To consider what role the physician or other health care providers should play in addressing a child's health concerns within the public school setting.

Program Observation--Suggested Outline:

- ❖ Identify the components of the program.
 - ◆ In which type of classroom do the children receive special education services (e.g., regular classroom, resource room, self-contained classroom)?
 - ◆ How many children are in the classroom?
 - ◆ What is the daily schedule?
 - ◆ How often throughout the day are the children with special needs with their non disabled peers?

- ❖ Identify the special services being provided to the child.
 - ◆ Are children receiving specialized instruction? Are any other services being provided (e.g., physical or occupational therapy, speech and language therapy, counseling, assistive technology, nursing, or nutrition)?
 - ◆ Do any of the children have an aide or paraprofessional providing assistance? Who accompanies them to the regular classroom? What type of assistance is being provided? Does the paraprofessional also provide assistance to other children?
 - ◆ Do the therapists or special educator consult with the regular education teacher to carry over intervention? How often is consultation/support available?
 - ◆ Are any assistive devices being used (e.g., wheelchair, alternative communication device, computer, modified seating)? Is the staff provided release time for training in the use of these devices?
 - ◆ Are other children involved in the activities with the related service staff?
 - ◆ Are the services provided age-appropriate?

- ❖ Identify how disabilities or special health care needs impact the children's ability to participate in classroom activities.
 - ◆ Are the children included in all classroom activities?
 - ◆ What accommodations need to be made to include the children in all classroom activities?

- ◆ How much social interaction is there between the children with special needs and the other children?
- ◆ Do the children with special needs have friends?
- ◆ Do friendships carry over to home and community?

- ❖ Identify the positive elements of the individualized education program as you observe them.
 - ◆ What appears to be going well for the children?

- ❖ Discuss with the teacher any of his or her concerns pertaining to the children with special needs.
 - ◆ Does the teacher identify any need for support regarding health care needs?
 - ◆ Is training in modifications in curriculum, technology, adaptive devices, alternative communication, and fostering peer relationships made available?
 - ◆ What environmental modifications were made for the students?
 - ◆ How frequently is inservice training offered? Are they mandated or optional?
 - ◆ How frequently does the teacher communicate with other team members?
 - ◆ How frequently does communication occur between home and school?

- ◆ What are the challenges of inclusion?
- ◆ What is his or her experience with the transition process?

- ❖ Discuss the service delivery team.
 - ◆ Who are the members of the service delivery team?
 - ◆ Does the team include a physician? How is he or she involved?
 - ◆ Is there a team leader or appointed case manager? What role does he or she play?
 - ◆ How are therapists included in the team?
 - ◆ How are paraprofessionals included in the team?
 - ◆ Does the team appear to be well coordinated?

Middle or High School

Purpose:

- ❖ To gain firsthand knowledge of ways in which special education services may be provided to students with disabilities and special health care needs at the middle or high school level.

- ❖ To consider how students with disabilities and/or special health care needs can be included in all middle or high school activities (classes, sports, clubs, intramurals) with appropriate and creative supports.

- ❖ To consider the role of the physician and other health care providers in addressing medical issues which impact a student's full participation in middle or high school activities.

Program Observation--Suggested Outline:

- ❖ Identify the components of the program.
 - ◆ What is the daily schedule?
 - ◆ What types of specialized services do students receive?
 - ◆ Do the IEPs for students include preemployment preparation, work related skills, job coaching, job placement?
 - ◆ Do the IEPs for students include functional skills (independent living, community living)?
 - ◆ How often do the students participate in activities with peers who do not have disabilities?
 - ◆ Do the students participate in academic classes with peers who do not have disabilities and/or special health care needs?
 - ◆ Are services provided in an age-appropriate manner?
- ❖ Identify special services and modifications implemented to ensure that students succeed.
 - ◆ Are any students receiving specialized instruction? How? Where is this provided?

- ◆ Are any students receiving any related services (physical therapy, occupational therapy, speech/language therapy, nursing, assistive tech)? Where? How is this provided?
 - ◆ Do any students receive support from an aide/paraprofessional? Where? How is this provided?
 - ◆ Do the special educators/therapists consult with each other and with regular educators, club advisors, etc.? How often?
 - ◆ Are any assistive devices being used by any students in this program (computer, communication board, etc.)?
 - ◆ Is staff provided release time for training in the use of the technology?
 - ◆ Do any students require medical services, CIC, a ventilator, medication?
 - ◆ Do IEPs contain goals for learning independence in health care?
- ❖ Identify how disabilities and/or special health care needs may impact social, academic, and physical participation in middle or high school activities.
- ◆ Are students given a choice in selecting courses?
 - ◆ What accommodations must be made to include students in social, academic, and physical activities?
 - ◆ Are modifications to classes, physical opportunities, and social activities age-appropriate?

- ◆ How much opportunity do students have to interact with typical peers in social settings?
 - ◆ Where does most of the social interaction take place?
 - ◆ Do students have typical peer friendships?
 - ◆ Are friendships school-based?
 - ◆ Do friendships generalize to the community (movies, pizza parties, pep rallies, “hanging out”)?
 - ◆ How do other students perceive the students with special needs?
 - ◆ Do other students feel that students with special needs contribute positively to the school community?
- ❖ Identify the service delivery team.
- ◆ Does the team include a physician?
 - ◆ Is there a team leader or appointed case coordinator for each student? What role does he or she play?
 - ◆ Are students included on the team? How are the students involved?
 - ◆ How are therapists included on the team?
 - ◆ How are other educators (biology teacher, physical education teacher, computer instructor) included in this team?
 - ◆ Are paraprofessionals included on the team?

- ◆ Are team members offered inservice training in the use of technology, assistive devices, alternative communication, and fostering peer relationships? Are inservice trainings mandated? Optional?

- ❖ Identify the positive elements of this program.

- ❖ Identify the challenges involved in meeting the academic, social, and physical needs of students in this program.

COMPONENT THREE: SPECIAL EDUCATION OR EARLY INTERVENTION PROGRAM VISIT ON PATIENT FROM THE CONTINUITY CLINIC

Location and Times:

You will arrange to observe a child from your continuity clinic at the child's special education or early intervention program. The visit will last from one to two hours and will be scheduled based on your block schedule and the availability of the program.

Format:

Observe a child's classroom or early intervention program to see what a typical day is like for the child. The child's program may be located in a school, the home, a daycare center, library, recreation department, or community play group. You should talk with the regular teacher, special education teacher, school nurse, principal, early interventionist, daycare provider, and other related support staff implementing the program. Please refer to the guideline appropriated for your visit, as listed on page 59.

Resident's Responsibilities:

You are responsible for your own transportation to the school, home, or program. Staff should be interviewed using the guidelines for the particular visit, in addition to your own prepared questions.

You should complete the *Resident Self-Evaluation* form for either the early intervention (center-based) program or special education (elementary, middle, or high school) program visit. Provide a copy of the *Performance Rating by Preceptor* to the early intervention provider or teacher.

GUIDELINES FOR SPECIAL EDUCATION OR EARLY INTERVENTION PROGRAM VISIT ON PATIENT FROM THE CONTINUITY CLINIC

Special Instructions:

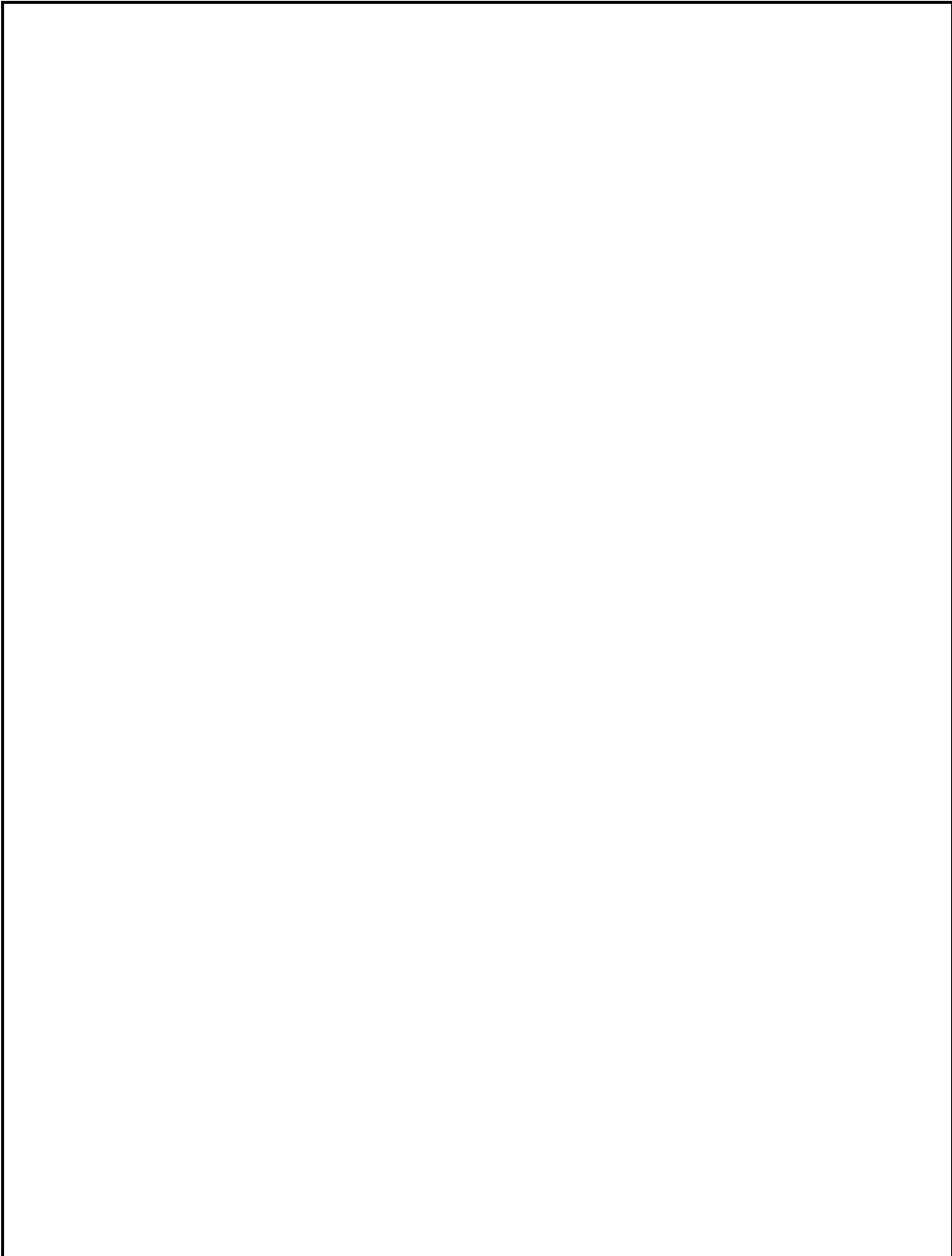
Depending on the type of visit, please refer to the guidelines as described below.

Community-Based Early Intervention Program Visit: Guidelines for Community-Based Early Intervention Program, Early Intervention Manual, page 67.

Special Education Program Visit--Elementary, Middle, or High School: Guidelines for Special Education Program Visit: Elementary, Middle, or High School, Special Education Manual, page 47.

All self and preceptor evaluation forms will be provided by the project coordinator. Please be sure to select the correct forms, depending on which type of visit you have arranged. Prior to your visit contact:

Physicians Training Project Coordinator
University of Connecticut
A.J. Pappanikou Center for Developmental Disabilities
(860) 679-1500



COMPONENT FOUR: SPECIALTY CLINIC VISIT

Location and Times:

You will be scheduled to attend a specialty clinic for one half day based on your interests and schedule.

Format:

There are two formats for a specialty clinic visit:

- ❖ Accompany a family you have met through your continuity clinic to a scheduled visit in a specialty clinic (please refer to *Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs Within Continuity Rotation* in Appendix A of the Family-Centered Care manual).

OR

- ❖ Attend a specialty clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time you will interview at least one family. See *Guidelines for Specialty Clinic Visit Family Interview*.

Resident's Responsibilities:

Prior to attending the specialty clinic, please complete some independent reading about the medical issues associated with the disability or condition treated in this clinic.

During the clinic visit follow these procedures:

- ❖ Inform the preceptor/family support person that you are there to observe and learn about that specialty from the family/child point of view as part of the Children with Disabilities curriculum experience.
- ❖ Be introduced (by the preceptor or family support person) to one or two families that you will follow during the visit.
- ❖ Follow at least one family throughout the entire appointment. For example, stay with the family as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
- ❖ Observe and interact with the family (see *Guidelines for Specialty Clinic Visit Family Interview*).
- ❖ Participate in a debriefing session with the preceptor, family support person, or specialty clinic team.
- ❖ Complete the *Resident Self-Evaluation: Specialty Clinic Visit*.
- ❖ Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

GUIDELINES FOR SPECIALTY CLINIC VISIT FAMILY INTERVIEW

Purpose:

- ❖ To gain a better understanding of how to provide care for children with disabilities and/or special health care needs, including recognizing the impact of disabilities and special health care needs on childhood development, obtaining knowledge of the array of services available for children with special needs, and learning how to coordinate comprehensive medical care for children with special health care needs.
- ❖ To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.
- ❖ To gain an in-depth awareness of how clinic visits are viewed through the eyes of the child and family.

Family Interview--Suggested Outline:

- ❖ Find out about the family composition, including who lives in the home, where they live, language spoken at home, sources of income, etc.
- ❖ What is a typical day/week like for this child and family?
- ❖ Identify the family's perceptions of the child's needs with regard to the home environment, school or child care program, and health care system.

- ❖ Does the family feel that these needs are being adequately addressed?
- ❖ What types of changes can be made, if any?
- ❖ If appropriate, ask for the child's input about this clinic visit. What are his or her concerns, questions, priorities, things he likes about coming, dislikes, feelings, etc.?
- ❖ What types of social supports does the family have?
- ❖ How was the child referred to the clinic? Is this an initial visit or follow-up visit?
- ❖ How did the family get to the clinic? Is transportation an issue?
- ❖ What does the family feel is the purpose of today's appointment?
- ❖ What types of questions do the family members have for the medical team?
- ❖ How comfortable does the child appear to be? The family?

APPENDICES

- A: Blank Individualized Education Plan, Procedural Safeguards and One Sample
- B: Assistive Technology Resources
- C: Reprint of: American Academy of Pediatrics, Committee On Children with Disabilities (2000). Provision of Educationally-Related Services for Children and Adolescents with Chronic Diseases and Disabling Conditions. *Pediatrics*, 105 (2), 448-451.
- D: A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA
- E: Connecticut Transition Legislation and Building a Bridge: Transition Planning
- F: Free Appropriate Public Education for Students with Handicaps: Requirements Under Section 504 Of The Rehabilitation Act of 1973
- G: Related Federal Laws: Air Carriers Access Act of 1986; Rehabilitation Act of 1973; and Fair Housing Amendments Act of 1988

Related Connecticut Laws and Codes: Connecticut Human Rights Statutes and Connecticut State Building Codes
- H: Resources: National Disability and Related Organizations (Both General and Specific To Disability), Independent Living Centers in Connecticut, ADA Information Services, and Connecticut State Resources

APPENDIX A

**BLANK INDIVIDUALIZED EDUCATION PLAN, PROCEDURAL SAFEGUARDS,
AND ONE SAMPLE**

APPENDIX C

REPRINT OF:

American Academy of Pediatrics, Committee on Children with Disabilities (2000). Provision of Educationally-Related Services for Children and Adolescents with Chronic Diseases and Disabling Conditions. Pediatrics, 105 (2), 448-451 .

APPENDIX B

ASSISTIVE TECHNOLOGY RESOURCES

Assistive Technology Resources

- ◆ Annual Computer Technology Directory
Exceptional Parent
P.O. Box 3000
Denville, NJ 07834-9919

- ◆ Apple Computer Resources in Special Education and Rehabilitation
DLM
One DLM Park
Allen, TX 75002
1-800-537-5030

- ◆ Connecticut's Assistive Technology Resource Directory
Special Education Resource Center
25 Industrial Park Road
Middletown, CT 06457-1520
860-632-1485

- ◆ ConnSAC
Judy Manuel
21 Heather Court
Cromwell, CT 06416

- ◆ ConnSENSE Bulletin
Chauncy N. Rucker
860-423-7880

- ◆ Hyper ABLE DATA Site
Steve Krasner
Special Education Resource Center
25 Industrial Park Road
Middletown, CT 06457-1520
860-632-1485

- ◆ International Society for Augmentative and Alternative Communication
P.O. Box 1762, Station R
Toronto, Ontario
Canada M4G4A3
416-421-8377

- ◆ RESNA
The Association for the Advance of Rehabilitation Technology
Washington
1101 CT Avenue, N.W.
Suite 7000
Washington, D.C. 20036
202-857-1199

- ◆ Resource Directory
Closing the Gap
P.O. Box 68
Henderson, MN 56044

- ◆ Resource Guide for Persons With Speech or Language Impairments
IBM National Support Center for Persons with Disabilities
P.O. Box 2150
Atlanta, GA 38055

- ◆ TECH ACT
John Ficarro, Project Coordinator
Department of Social Services
Bureau of Rehabilitative Services
11th Floor
25 Sigourney Street
Hartford, CT 06106

- ◆ Trace Research and Development Center on Communication, Central
and Computer Access for Handicapped Individuals
A-151 Waisman Center
1500 Highland Avenue
Madison, WI 53705
608-263-6966

APPENDIX D

A COMPARISON OF PRESCHOOL (PART B) AND INFANT/TODDLER (PART C) PROGRAMS OF IDEA

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Eligible Children	<p>3- to 5-year-olds with developmental delays:</p> <p>At state discretion, eligibility may include children experiencing developmental delays, as defined by state in one or more of the following areas:</p> <ul style="list-style-type: none"> ◆ Physical ◆ Cognitive ◆ Communication ◆ Social or emotional ◆ Adaptive 	<p>Birth to 2-year-olds:</p> <ol style="list-style-type: none"> 1. Showing developmental delays (as defined by state). 2. Having a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. <p>Areas of development:</p> <ul style="list-style-type: none"> ◆ Cognitive ◆ Physical ◆ Communication ◆ Social or emotional ◆ Adaptive <ol style="list-style-type: none"> 3. Children “at risk” for developmental delay at state’s discretion, who are in need of early intervention.

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Services	<p>Special education and related services documented on Individualized Education Plan include but are not limited to:</p> <ul style="list-style-type: none"> ◆ Audiology ◆ Counseling services (by qualified social workers or others) ◆ Early identification ◆ Medical services (for diagnostic purposes) ◆ Occupational therapy ◆ Parent counseling and training ◆ Physical therapy ◆ Psychological services ◆ Recreation ◆ School health services ◆ Speech pathology ◆ Social work services in the schools ◆ Transportation 	<p>Early intervention services documented on Individualized Family Service Plans include but are not limited to:</p> <ul style="list-style-type: none"> ◆ Assistive technology devices and services ◆ Audiology ◆ Early identification, screening, and assessment ◆ Family training, counseling, and home visits ◆ Health services ◆ Medical services (for diagnostic purposes) ◆ Nursing services ◆ Nutrition services ◆ Occupational therapy ◆ Physical therapy ◆ Psychological services ◆ Service coordination ◆ Social work services ◆ Special instruction ◆ Speech-language pathology ◆ Transportation and related costs ◆ Vision services

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Individualized Plans	<p>Individualized Education Plan (IEP):</p> <ul style="list-style-type: none"> ◆ A statement of the child’s present levels of educational performance. ◆ A statement of annual goals, including short-term instructional objectives. ◆ A statement of the specific special education and related services to be provided to the child, and the extent to which the child will be able to participate in regular education programs. ◆ The projected dates for initiation of services and the anticipated duration of the services. ◆ Appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short-term instructional objectives are being achieved. ◆ Transition services. ◆ At local or state discretion, and with the concurrence of the family, 3- to 5-year-olds may have an IFSP rather than an IEP, so long as IEP requirements are met. 	<p>Individualized Family Service Plan (IFSP):</p> <ul style="list-style-type: none"> ◆ A family-directed assessment of the resources, priorities, and concerns of the family. ◆ A statement of the natural environments in which early intervention services shall appropriately be provided. ◆ A statement of the child’s present levels of development. ◆ With the concurrence of the family, a statement of the family’s strengths and needs related to enhancing the development of the child. ◆ A statement of the major outcomes expected to be achieved for the child and family, and the criteria, procedures, and time lines used to determine: <ol style="list-style-type: none"> 1. The degree to which progress toward achieving the outcomes is being made. 2. Whether modification or revision of the outcomes or services is necessary. ◆ A statement of the specific early intervention services necessary to meet the unique needs of the child and family to achieve the outcomes identified, including: <ol style="list-style-type: none"> 1. Frequency, intensity, location, and method of delivering services. 2. The payment arrangement, if any. 3. Other services not required by this act but needed by the child and steps to secure these services from other sources. ◆ The projected dates for initiation of services and the anticipated duration of those services. ◆ The name of the service coordinator, someone who is qualified to carry

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Integration	<p>“Least Restrictive Environment”:</p> <p>“To the maximum extent appropriate, children with disabilities...are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”</p>	<p>“Natural Environments”:</p> <p>“To the maximum extent appropriate, (services) are provided in natural environments, including the home and community settings...in which children without disabilities participate.”</p>
Lead Agency	State education agency is lead agency	Governor-designated lead agency

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Advisory Panels	<p>State Special Education Advisory Panel:</p> <ul style="list-style-type: none"> ◆ Appointed by Governor ◆ Members include: <ul style="list-style-type: none"> • Consumers • Parents • Teachers • Special education administrators • State and local officials 	<p>Interagency Coordinating Council:</p> <ul style="list-style-type: none"> ◆ Appointed by Governor ◆ At least 15 members but no more than 25 (unless approved) ◆ Members include: <ul style="list-style-type: none"> • 20% parents • 20% providers • One legislator • One personnel trainer • One state education agency representative of the 3-5 program • One state insurance representative • Chair may be appointed by Governor from the members or the Governor shall have the members designate; no lead agency representative may serve as chair ◆ May have birth to five focus ◆ Shall advise on transition ◆ Establishes a Federal Interagency Coordinating Council B-5
Participation of Other Agencies	Must meet state standards and be under general supervision of state education agency.	Lead agency must monitor programs used to carry out Part C whether receiving Part C monies or not.

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
Implementation Timeline "Mandate"	All eligible children must be receiving services by FY 1991 (school year 1991-1992) or sanctions are applied.	<p>All eligible children must be receiving services no later than beginning of state's fifth year of participation in program if the state continues to participate.</p> <p>Provides for "differential funding" which authorizes a maximum of 2 one-year extensions for states that are unable to meet their fifth year requirements within 5 years of participation if the Governor requests an extension and the secretary grants it; funding is at a reduced level for those states awarded extensions.</p>
Application for Funds	State education agency applies every 3 years.	Lead agency applies every year and every 3 years after full implementation.
Basis for Allocation of Dollars to State	<p>Preschool children generate funding from both the Part B state grant program, as well as the Part B -- Section 619 (preschool) program.</p> <p>Each state receives funding in proportion to the number of 3 to 5-year-olds served on December 1 of the previous year.</p> <p>No state shall receive less than \$450,000 for administration; preschool grants authorized up to \$1,500 per child.</p>	<p>Each state receives funding in proportion to its general population of birth to 2-year-olds, except not less than .5% of the total federal appropriation.</p> <p>No state shall receive less than \$500,000.</p>

A Comparison of Preschool (Part B) and Infant/Toddler (Part C) Programs of IDEA after the 1997 Amendments (P.L. 105-117)

ISSUE	PRESCHOOL (Part B)	INFANT/TODDLER (Part C)
State Use of Funds	At least 75% of funds must flow to local education agencies on a pro-rated basis; up to 20% of funds may be used at state's discretion; up to 5% of funds may be used for administrative purposes; shall not supplant; use for "excess cost."	<p>To plan, develop, and implement statewide system of services; funds cannot be used for services that are provided or paid for through other sources; Part C funds are used as a last resort and are to be distributed equitably across geographic areas; shall not supplant.</p> <p>Allows for flexible use of both Part B and Part C funds during the year the child turns 3 years of age; allows for the use of both Part B and Part C funds for the planning of a birth to 5 seamless system of services.</p>
Cost to Parents	All special education and related services must be available at no cost to parents.	State must establish a sliding fee scale if state law permits, however, families may not be denied services because of inability to pay; certain services must be provided at no cost; child find, evaluation and assessment, service coordination, development and review of IFSP, procedural safeguards; if a state provides "a free, appropriate public education" (FAPE) from birth--all services are at no charge.

APPENDIX E

CONNECTICUT TRANSITION LEGISLATION AND BUILDING A BRIDGE: TRANSITION PLANNING

APPENDIX F

**FREE APPROPRIATE PUBLIC EDUCATION FOR STUDENTS WITH HANDICAPS:
REQUIREMENTS UNDER SECTION 504 OF THE REHABILITATION ACT OF 1973**

APPENDIX G

RELATED FEDERAL LAWS:

Air Carriers Access Act of 1986

Rehabilitation Act of 1973

Fair Housing Amendments Act of 1988

APPENDIX H

RESOURCES:

National Disability and Related Organizations (both general and specific to disability)

Independent Living Centers in Connecticut

ADA Information Services

Connecticut State Resources