

# **Premature Infants**

## **Guidelines**

### **for**

# **Early Intervention Services**



*For infants who are referred into the early intervention system due to concerns pertaining to premature birth*

**"Tomorrow's Success Begins Today"**

# Early Intervention Services Guidelines for infants who are referred into the early intervention system due to concerns pertaining to premature birth

## Tennessee’s Early Intervention System

*Services for Infants and Toddlers with Disabilities under  
the Individuals with Disabilities Education Act (IDEA)  
Part C*

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*In addition, appreciation is also given to Dr. Maureen Hack, Neonatologist, Children's Hospital, Cleveland, OH for her review and comments regarding the guidelines for premature infants.*

## Preface

In June, 1999 the Department of Education (as the lead agency for the early intervention system in Tennessee), Division of Special Education, Office of Early Childhood formed the Committee for Premature Infants. The purpose of this committee is two fold:

1. To establish eligibility guidelines for premature infants for Tennessee's Early Intervention System.
2. To establish guidelines for best practices for serving eligible premature infants in Tennessee's Early Intervention System.

In order to ensure consistency in eligibility determination, these guidelines were developed for professionals who may identify infants as possibly eligible for early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA). (See Appendix F for description of IDEA.)

The Committee for Premature Infants recognizes that aspects of these guidelines related to eligibility determination also pertain to newborn infants. The mandate given to the Committee for Premature Infants was to address the needs of infants who are referred into the early intervention system due to concerns related to premature birth. Newborn infants without concerns pertaining to prematurity are frequently referred into the early intervention system for concerns due to other factors. Eligibility for early intervention services for these infants is also determined through a multidisciplinary evaluation.

## **Referral Process into Tennessee's Early Intervention System**

Infants who have been referred into the early intervention system due to concerns pertaining to premature birth receive a multidisciplinary evaluation and, as appropriate, early intervention services. Referrals into Tennessee's Early Intervention System (TEIS) are made by anyone who has identified a child who may be eligible for early intervention services based on Tennessee's Definition of Developmental Delay (Appendix A). TEIS has a mechanism of referrals for young children birth through age two through the nine district TEIS offices in Tennessee (Appendix G).

Physicians, NICU personnel, or parents should refer potentially eligible children, including infants who have concerns pertaining to premature birth, through the district's single point of entry or through the statewide point of entry (1-800-852-7157). Any child who is suspected of having a developmental delay or a physical or mental condition that is likely to result in a developmental delay is potentially eligible for early intervention services. TEIS will arrange for a multidisciplinary evaluation to determine eligibility for early intervention services.

At the initial referral a service coordinator is assigned to the child and family. The TEIS office has a service coordinator who is primarily responsible for receiving referrals of infants who have concerns pertaining to premature birth. The service coordinator will contact the referral source and the family in order to obtain basic information regarding the status of the infant who has been referred. The TEIS service coordinator and personnel from the NICU, along with the family, will collaborate in order to identify the appropriate procedures for completing the multidisciplinary evaluation to determine if the infant is eligible for early intervention services.

# Overview of Eligibility Determination

In order to receive early intervention services under Part C in Tennessee, an infant or toddler must be determined eligible for early intervention services. An eligible child is an infant or toddler with a disability. In Tennessee the term “infant or toddler with a disability” means an individual from birth through age two who needs early intervention because he or she meets the criteria for Tennessee’s Definition of Developmental Delay which consist of:

1. Developmental Delay (Part A)  
or
2. Diagnosed Condition (Part B)  
or
3. Informed Clinical Opinion.

Under Part A of Tennessee’s Definition of Developmental Delay, the child must be functioning at 25% below chronological age in two or more developmental domains or 40% below chronological age in one developmental domain as determined by administration of an eligibility evaluation. Part B refers to an infant or toddler whose eligibility is based on a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Informed Clinical Opinion may be used to determine eligibility when standardized measures will not accurately reflect the child’s developmental status.

## Evaluation Procedures

All children referred to Tennessee’s Early Intervention System receive a multidisciplinary evaluation to determine eligibility for early intervention services. The following guidelines for conducting a multidisciplinary evaluation, which are outlined in *TEIS Individualized Family Service Plan Manual*, must be utilized in determining eligibility of an infant or toddler.

## Guidelines for Multidisciplinary Evaluations

- The multidisciplinary evaluation is completed within 45 days of the child’s referral to the early intervention system. Circumstances that prevent the completion of the evaluation within 45 days are clearly documented.
- A minimum of two different disciplines is involved in the evaluation and/or assessment. The disciplines are selected to best meet the needs of the child.
- The evaluation for eligibility must include at least one of the suggested tools for evaluation for eligibility (which are found in *TEIS Individualized Family Service Plan Manual*) and a parent interview.
- The evaluations are conducted and interpreted by qualified personnel and are based on informed clinical opinion.
- An evaluation includes the following:
  - ♦ A review of pertinent records and information related to the child’s current health status and medical history and
  - ♦ Determination of the child’s abilities, limitations, and functioning in:
    - Cognitive development,
    - Physical development (including vision and hearing),
    - Communication development,
    - Social-emotional development, and

- Adaptive development.
- Each family’s culture and communication needs are considered when planning and implementing the evaluation and/or assessment.
- Interpreters are used when working with families for which English is a second language and for families using other forms of communication (e.g., sign language).

## **Personnel Requirements for Evaluators**

In Tennessee, children who are referred to the early intervention system are determined eligible based on a multidisciplinary evaluation. Multidisciplinary means the involvement of two or more disciplines or professions in the provision of an integrated and coordinated evaluation. Eligibility evaluations are completed by an early childhood specialist and a health or family-focused professional. All personnel who complete the evaluation for eligibility shall have current certification, licensure, or comparable requirements of their profession. The disciplines involved in conducting the evaluation shall be selected based on the child’s needs.

## **Eligibility for Early Intervention Services**

Eligibility for early intervention services depends on the presence of developmental delay or the presence of a condition likely to result in developmental delay. Any child from birth through age two is eligible if he or she meets Tennessee’s eligibility requirements as stated in Tennessee’s Definition of Developmental Delay. Tennessee’s Definition of Developmental Delay is found in Appendix A.

## **Documentation of Eligibility**

Infants and toddlers who meet the criteria for Tennessee’s Definition of Developmental Delay based on the Guidelines for Premature Infants are eligible for early intervention services. The eligibility determination for early intervention services is documented by completing the forms found in Appendix B.

## Prematurity

For infants who are referred into the early intervention system due to concerns pertaining to prematurity, an eligibility determination will be made based on a multidisciplinary evaluation, which includes the following:

- Completion of Professional Verification Form, or documentation of diagnosed physical or mental condition that has a high probability of developmental delay, with a qualified professional's signature;
- A review of pertinent records and information related to the child's current health status and medical records; and
- Determination of the child's abilities, limitations, and functioning in all developmental domains.

No single procedure is used as the sole criterion to determine a child's eligibility. In addition to the above documentation which states that the infant has the identified biological factors that have been determined as having a high probability of resulting in developmental delay, an assessment is completed which determines the child's abilities, limitations, and functioning in all developmental areas. Also, pertinent records, which provide information related to the child's health status, are reviewed.

### Qualified Personnel

A health professional shall be one of the disciplines involved in the provision of the multidisciplinary evaluation to determine eligibility for an infant who has been referred due to concerns pertaining to prematurity.

The Professional Verification Form, or documentation that the infant has the identified biological factors which have been determined to have a high probability of resulting in developmental delay, should be completed by at least one of the following professionals:

- Neonatologist
- Pediatrician
- Primary care physician
- Registered nurse
- Nurse practitioner
- Social worker affiliated with NICU
- Health professional affiliated with NICU or NICU follow-up clinic
- Family nurse practitioner (FNP)
- Pediatric nurse practitioner (PNP)

## Premature Infant Criteria

Tennessee's Definition of Developmental Delay includes diagnosed physical or mental conditions that have a high probability of resulting in developmental delay. A child with a diagnosis of prematurity may be eligible for early intervention services through Part C if the child meets Tennessee's eligibility requirements as stated in Tennessee's Definition of Developmental Delay. A premature infant may be eligible if:

--He or she is born at a gestational age of less than 30 weeks

OR

--He or she is born at a gestational age of 30-36 weeks and meets at least one of the following criteria:

--Intrauterine growth retardation (IUGR) less than 10<sup>th</sup> percentile

--Hypoxic ischemic encephalopathy

--Seizure activity in neonatal period

--Meningitis in neonatal period

--Intraventricular hemorrhage (IVH) grade III/IV

--Abnormal CT/US findings, including ischemia, thrombosis, significant hydrocephalus, major malformations, disorders of myelination

--Microcephaly at less than 10<sup>th</sup> percentile for gestational age

--Metabolic derangement: inborn error of metabolism, prolonged hypoglycemia more than eight hours, bilirubin reaching exchange level

OR

--He or she is born at a gestational age of 30-36 weeks and meets at least two or more of the following criteria:

--APGAR score of less than three at five minutes

--Prolonged ventilation for apnea or hypoventilation for more than 48 hours

--Prolonged hypoxemia for greater than 24 hours

--Hypotonia for more than 48 hours

--Prolonged hypotension for more than eight hours

## Assessment

In addition to the completion of the eligibility documentation, an assessment of all developmental domains should be completed in order to determine the unique needs of the infant in terms of each of the developmental areas, including the identification of services appropriate to meet those needs prior to the completion of the initial Individualized Family Service Plan (IFSP). In the event that the infant is not appropriate for formal assessment procedures, observations from the Neonatal Intensive Care Unit (NICU) or by an early interventionist shall be utilized in order to determine the child's abilities, limitations, and functioning in all developmental domains. More formal assessments dependent upon the child's ability to tolerate assessment procedures may utilize one or more of the following assessment tools:

- Assessment, Evaluation, and Programming System for Infants and Children (AEPS)
- Battelle Developmental Inventory
- Carolina Curriculum for Infants and Toddlers with Special Needs (CCITSN)
- Hawaii Early Learning Profile
- Neonatal Behavior Assessment Scale (NBAS)
- Test of Sensory Functions in Infants (TSFI)

A complete description of these assessment tools is provided in Appendix C.

Additional information regarding evaluation and assessment practices may be found in *TEIS Individualized Family Service Plan Manual*.

## Re-Evaluations

Re-evaluations are the procedures used by qualified personnel to determine a child's continuing eligibility for early intervention services consistent with Tennessee's Definition of Developmental Delay (Appendix A). The re-evaluation process follows the same procedures as the initial evaluation.

Re-evaluations to determine continuing eligibility are completed prior to the annual IFSP, if needed, or more often if the IFSP team determines re-evaluations to be appropriate as indicated by progress through on-going assessments or if there is a change in the child's diagnosed physical or mental condition.

### Re-Evaluation of Infants Determined Eligible Based on Prematurity

Infants who have been determined eligible for early intervention services because they meet the criteria for prematurity will receive a re-evaluation to determine continued eligibility by age two.

- Infants, who have been determined eligible for early intervention services because they meet the criteria for prematurity and have been determined to have an additional diagnosed physical or mental condition that has a high probability of resulting in developmental delay will not require a re-evaluation at age two to determine continuing eligibility. At the time the child is determined to have the additional diagnosed condition that is likely to result in developmental delay, the child's current eligibility identification should be updated and documented on the Eligibility Documentation form (see Appendices A & B).
- Infants, who have been determined eligible for early intervention services because they meet the criteria for eligibility and have not been determined, prior to age two, to have an additional diagnosed physical or mental condition that has a high probability of resulting in developmental delay, should receive a multidisciplinary evaluation to determine continued eligibility. The multidisciplinary evaluation procedures for continued eligibility are identical to those procedures used to determine initial eligibility.

## **Eligibility Determination for Premature Infants Who Do Not Meet the Premature Criteria**

*For infants who are referred into the early intervention system due to concerns regarding premature birth and do not meet the Premature Infant Criteria.*

A premature infant who does not meet the Premature Infant Criteria and has not been determined to have an additional diagnosed physical or mental condition that has a high probability of resulting developmental delay will receive a multidisciplinary evaluation to determine eligibility for early intervention services based on the identification of developmental delays as specified in Tennessee's Definition of Developmental Delay, Part A (Appendix A).

Determining developmental delays in a premature infant is unlike determining developmental delays in an older child. Much of the infant's multidisciplinary evaluation is based on observational data, and much of the data comes from parents, nurses, caregivers and others who are involved in the child's life. Each of these informants provides different perspectives on the child's development. One factor to consider is the consistency in the various informants' observations to determine if the child's skills are consistent across the various settings. Settings for observations include day-to-day interactions such as eating, sleeping, and feeding routines.

No single procedure is used as the sole criterion to determine a child's eligibility for early intervention services. At least two disciplines must be involved in determining the child's eligibility. At least one of the "Evaluation Tools for Determining Eligibility for Early Intervention Services" (see IFSP Manual) must be used to determine eligibility under Part A of Tennessee's Definition of Developmental Delay. The evaluation instrument used to determine eligibility should be based on the needs of the child and follow the administration and scoring procedures as specified by the evaluation tool's guidelines.

### **Adjusted or Corrected Age**

It has been common practice to correct for prematurity for the first two years of life, but there has been little research regarding the appropriateness of this practice. Research by Siegel (1983) and Sugita, et al (1990) both conclude that in normal cases at one year of age and after there were no significant differences between the predictive value of the corrected and uncorrected developmental quotient scores as to later IQ scores. The opinion of both researchers is that it does not matter which scores are used. Barrera and others (1987) analyzed the use of corrected and uncorrected scores. They concluded that both corrected and uncorrected score be considered, given parental concerns and the need for early identification of developmental delays.

A study by Miller (1984) found that the use of correcting for prematurity resulted in over correction, which causes difficulty in recognizing abnormality in acquisition of developmental milestones. These researchers agreed with Barrera in the benefits of recording both corrected and uncorrected developmental quotients. However, the use of uncorrected developmental scores was considered a more sensitive index of abnormality. For the purpose of determining eligibility for early intervention services, the evaluation results are based on uncorrected scores. With the exception of the Bayley Scales, standardization of the evaluation tools for determining eligibility did not include premature infants. The evaluator should follow administration procedures as specified for the evaluation tools that are being utilized.

## **Collaboration with Neonatal Intensive Care Units and Tennessee's Early Intervention System**

It is recommended that the district Tennessee's Early Intervention System (TEIS) office and the Neonatal Intensive Care Units (NICU) within each district collaborate to develop procedures for referring infants to the TEIS offices in order to determine eligibility for early intervention services. In addition to referral procedures, the NICU, NICU follow-up clinic and the district TEIS office should develop policies for implementation of early intervention services during an infant's hospitalization and after discharge from the hospital. The policies and procedures that are developed between the NICU and district TEIS office will vary depending on the needs and requirements of the participating agencies. The policies and procedures may be outlined in the form of a Memorandum of Understanding (MOU) or Interagency Agreement. The methods that the early intervention system within a district utilizes will vary depending on the needs of the NICU and the district TEIS office. Some districts may choose to develop written formal or informal agreements, while others may choose to engage in verbal discussion in order to develop procedures for collaboration with the district TEIS office and NICU.

In addition to the development of policies and procedures, training needs and technical assistance related to providing early intervention services to premature infants may be identified by the TEIS office and NICU. Requests for training or technical assistance may be made to the Office of Early Childhood, Division of Special Education, Department of Education.

### **NICU Referral Questionnaire: Summary of Results**

Neonatal Intensive Care Units (NICU) are an integral component in the identification of infants who may be eligible for early intervention services. In order to develop procedures for readily identifying infants who may be eligible for early intervention services, the Committee for Premature Infants requested information through questionnaires from each of the NICUs within Tennessee. The information gathered was compiled in order to assist in the development of the guidelines found in this document (see page 5) for referring infants from the NICU to the local TEIS office.

Questionnaires were sent to each of the nineteen NICUs in Tennessee (See Appendix D). Fourteen NICUs responded to the questionnaires. Results are based on the data from these fourteen questionnaires. Respondents included registered nurses, physicians, nurse practitioners, and social workers that are affiliated with a NICU.

The questionnaire centered on current practices by the NICU personnel in regard to referrals into the early intervention system. The NICUs were also asked to react to the Premature Infant Criteria.

Ten out of the fourteen NICUs stated that there was an established procedure for referring children to the early intervention system. Case managers or social workers facilitated most of the referrals from the NICUs. The case managers or social workers were also responsible for providing the family with information about the early intervention system. Nine of the fourteen NICUs have established criteria for determining which infants will be referred to TEIS. Five of the NICUs reported that there was a contact person within the TEIS office who had the responsibility for receiving referrals from the NICUs. The number of referrals from the NICU during the two months preceding the questionnaire varied from two in smaller hospitals to over thirty in a large metropolitan hospital.

Eight of the fourteen NICUs have an NICU follow-up clinic. Referrals are made to the early intervention system from the NICU follow-up clinics. In the two months preceding the questionnaire, referrals from the NICU follow-up clinics into the early intervention system ranged from one in smaller hospitals to twenty in a large metropolitan hospital.

Most of the NICUs and/or NICU follow-up clinics have developmental services for the infants that they serve. These services most frequently include physical therapy, but may also consist of occupational therapy and speech therapy.

In response to a review of the Premature Infant Criteria, eight of the fourteen NICUs reported the criteria would increase the number of referrals they made into the early intervention system. Six NICUs reported that there would be no effect on the number of referrals that they facilitated. The majority (13) of NICUs stated that the criteria accurately identifies children who are in need of early intervention services because they have a condition that has a high probability of resulting in developmental delay. The majority (13) of the NICUs also report that the Premature Infant Criteria are helpful in determining which children should be referred to the early intervention system.

## **Family-Centered Services in the Neonatal Intensive Care Unit**

The concept of the family-centered approach to service delivery places major emphasis on supporting and strengthening the family. Family-centered principles are rooted in the belief that family-centered early intervention services seek to build on and promote the strengths and competencies present in families. It is important that all supporting professionals who are involved in the care of infants and toddlers maintain the philosophy that families are unique and diverse. Each family is to be considered with a focus on the desires of that family for their child and for themselves (Bailey, 1992; McGonigel, 1991).

Professionals from a variety of disciplines will be collaborating in the provision of medical and early intervention services either in the Neonatal Intensive Care Unit (NICU) or upon the infant's discharge from the NICU. These professionals include pediatricians, nurses, social workers, infant development specialist, and physical, occupational, speech-language, and respiratory therapists. Within the NICU, family-centered services are based on the premise that services to the infant are meaningfully provided only within the context of the entire family. According to Thurman (1991), adherence to several guiding principles is necessary if family-centered services are to be provided in NICUs. The principles that he suggests are the need to:

1. Establish and maintain adaptive fit within the family and between the family and the service delivery system;
2. Provide services based on family identified needs and desires;
3. Foster family independence and empowerment while providing a stable ongoing support system; and
4. Recognize that families are a complex, dynamic, and ever-changing system.

Families will vary greatly in their decisions regarding the initiation, amount, and types of early intervention services for their premature infant. Professionals working within the NICU and early interventionists outside the NICU will need to be aware of the priorities and concerns of the premature infant's family during the decision making process for determining the appropriateness of early intervention services. Many early intervention services provided by physical, occupational, and speech-language therapists, as well as those provided by early interventionists can only be implemented when the infant has achieved a reasonable level of medical stability. However, professionals involved in early intervention services can provide information to parents as they prepare to take the infant home (Thurman, 1993). Most or all of these decisions regarding early intervention services can be made in conjunction with developing the Individualized Family Service Plan (IFSP), continuing care plan, and/or discharge plans.

Parents benefit when they are provided with information about their baby's condition from the time of admission to the NICU. As soon as the baby is medically stable, the family should begin participating, to the extent possible and desired, in the care of their baby (McCluskey-Fawcett et al., 1992). Some types of activities for family involvement that may be identified on an IFSP and/or discharge plan are:

Information regarding the basic care of the premature infant, medical care and terminology, and care and utilization of equipment;

How to monitor the unique needs of their infant, such as developmental milestones unique to preterm development;

Determining the extent of long term care with follow-up with professionals; and

Support services for the family such as parent support groups, parent-infant playgroups, day care, respite care, and other social services.

There is a strong inference that early intervention is effective for premature infants. Blair and Ramey (1997) have identified conclusions regarding the effectiveness of early intervention services for premature infants.

1. **Timing** Parent-focused interventions that began in the hospital produce positive results.
2. **Direct versus intermediary provision of services** Apparently both direct and intermediary provision of services appear to be equally effective when parents are targeted as well as the infants.
3. **Attention to individual differences in program delivery** Parent-focused interventions conducted for premature infants provide for engaging parents and involving them in caregiving routines. These programs pay special attention to individual differences.
4. **Intensity** When the activities are parent-focused, the number of developmentally stimulating exchanges between parents and infants is very high.
5. **Comprehensiveness** Parent-focused interventions focus on no one aspect of child development in particular other than the needs of the parent and child, encouraging the parents to become active participants in their child's growth and development.
6. **Maintenance of effects** The combining of child- and parent-focused intervention services is effective in developing stimulating transactions between caregivers and children. Efforts to increase parent participation are warranted.

In order for early intervention activities to occur in the NICU, the IFSP process must be flexible and responsive to the ever-changing needs of the infant and/or family. The service plans must be easy to implement and easy to revise. Unlike IFSPs that are completed outside the NICU which contain goals in developmental domains, the IFSP written in the hospital setting will contain activities that are more functional in nature such as feeding, sleeping, and social interaction. A total of three to five goals which are identified by the parents is common (Ploof, 1992).

## **NICU Parent Questionnaire: Summary of Results**

Family input was sought to assist in the process of developing best practice guidelines for serving eligible premature infants. A questionnaire was sent to 376 families of children in Tennessee who had been referred to state services due to low birth weight (< 1200 grams) between April 1999 and April 2000 to seek and utilize parental expertise in developing procedures for readily identifying infants who may be eligible for early intervention (EI) services. Forty surveys were returned. Parents were asked to respond to questions in four categories: 1) Public Awareness and Child Find, 2) Evaluation and Assessment, 3) Service Coordination, and 4) Services Received. The responses provided information about parental understanding of the early intervention referral process, preferences regarding timing and method of initial referral, and types and timing of services received both in the NICU and following discharge. Open-ended questions provided opportunities for families to provide suggestions for both NICU and TEIS staff for improvement of referral and implementation of

services. Results from each item surveyed are included in Appendix E in the Report on Responses to NICU Parent Questionnaire.

In summary, results of this parent survey indicate a need for continued and improved collaboration between TEIS and neonatal intensive care units in their combined efforts to address the medical and developmental needs of premature infants and their families. In regard to public awareness and child find, a need for information about TEIS in the NICU and in the NICU follow-up clinic was identified. Informational brochures would have been appreciated both in the NICU and during NICU follow-up clinics. Public awareness activities should also be conducted with NICU personnel.

The majority of parents learned about TEIS while they were in the NICU and were first contacted by a service coordinator in their home, following discharge from the hospital. Parents responding to the questionnaire understood why they were referred to TEIS, agreed to the referral, desired the referral, and felt that referrals were made at the appropriate time. Of the families who had been referred to TEIS, ninety-five percent indicated that they felt the referral was appropriate.

In regard to evaluations and assessment, most parents did not report a discussion about multidisciplinary evaluations for eligibility for early intervention services while they were in the NICU, although most parents reported they would like to have had access to information about early intervention services. Fifty-three percent of the respondents indicated that their child had received a multidisciplinary evaluation for eligibility for services through TEIS following discharge from the NICU. When asked how they would change the evaluation experience to better suit their family, eighty-one percent indicated they were pleased with the process and would make no changes. Nineteen percent of families did suggest changes, primarily related to reducing the volume of paper work and the time required to accommodate multiple evaluators.

Families were asked when they would prefer to be informed of the evaluation for early intervention services. Of the thirty-two families responding, sixty-nine percent would have liked to be informed while they are in the NICU, while twenty-eight percent preferred to wait until after hospital discharge. When asked if they would have chosen to have a TEIS service coordinator while they were in the NICU, sixty-eight percent of the thirty-one responding indicated that they would. When respondents indicated they preferred not to have a service coordinator while in the NICU, the primary reason given was related to a desire to have time to adjust to all that occurred since the infant's birth. Families expressed that this would give them time to adapt, settle in, and bond with their infant.

Almost all families who responded to the item regarding when the IFSP was first developed for their family indicated that they participated in the IFSP process after their child was discharged from the NICU. Families seem to be equally conflicted regarding whether an IFSP would be useful to them in the NICU or if they preferred to participate in this process following hospital discharge. For this reason, it is clear that a family-centered approach is essential. While the majority of families want information and referral to TEIS while in the NICU, development of the IFSP and delivery of services will be dependent on the individual needs of the child and family.

When invited to offer any recommendations regarding TEIS and the NICU, twenty-two responses were given. Of those, eight families offered kind words of praise and appreciation for the assistance given to their child and family by both TEIS and the NICU. One suggestion was made that NICUs refer all babies born at thirty weeks gestation or less to TEIS. One family preferred that TEIS contact them while they were in the NICU, while another family

preferred that information only be given while in the NICU, with follow-up contact after discharge. The suggestion was made that TEIS service coordinators strive to reduce the use of technical lingo, and more frequent contact with service coordinators was desired. Several families felt more awareness and information about TEIS should be made available.

Results presented in this report were collected from a small sample across the state of Tennessee. The length of the survey may have contributed to the response rate by negatively impacting a family's willingness to complete the questionnaire. Therefore, one must use caution in making broad assumptions based on the survey results. Having acknowledged that, it must also be stated that all families and all babies are unique. There is value to be gained from each individual experience.

It is clear from the survey that families want information from the start. TEIS and neonatal intensive care units across the state should be commended for their present collaboration, while acknowledging that we can always improve. Once a referral is made to TEIS and the service coordinator meets with the family, then the informed family will lead the way. Some families want services as soon as possible, while others have concerns that must take precedence for the time being. The family, team members, and the TEIS service coordinator should be able to determine a plan of action that suits the individual needs of a given family.

Input received from families via this survey only serves to strengthen the professional's ability to work cooperatively and effectively with families. Appreciation is expressed to the families who participated in this effort.

## Definitions

**Adjusted Age** The age a premature infant would be if he/she had been born on his/her due date. For example, a baby born two months prematurely has an adjusted age of six months when he/she is actually (chronologically) eight months old.

*Also known as **corrected age**.*

**APGAR score** A score ranging from 0 to 10 indicating a baby's physical condition immediately following birth.

**Apnea** Temporary cessation of breathing.

**Assessment** The initial and ongoing procedures used by qualified personnel throughout the period of a child's eligibility under Part C to identify:

- (1) The child's unique strengths and needs and the services appropriate to meet those needs;
- (2) The resources, priorities, and concerns of the family related to the development of the child;
- (3) The supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability; and
- (4) The current and potential activities, relationships, routines, and culture that constitute the child's natural environment.

**Bilirubin** The orange-colored or yellowish pigment in the bile. It is the accumulation of bilirubin that leads to jaundice in many cases, especially to physiologic jaundice of the newborn.

**Bilirubinemia** Presence of bilirubin in blood. Bilirubin is normally present in small amounts. However, in certain pathological conditions in which excessive destruction of red blood cells occurs, or in which there is interference with bile excretion, the amount is increased. In the newborn with erythroblastosis fetalis and greatly elevated bilirubin, exchange transfusion may be required.

**Chronological Age** Age determined from date of birth.

**Collaboration** (1) The establishment and maintenance of open communication and cooperative working relationships among service providers and other caregivers and the family when identifying goals and delivering care to children. (2) **Interagency Collaboration** is cooperative efforts between or among agencies to maximize resources on behalf of children with special needs and their families.

**Corrected Age** The age a premature baby would be if he had been born on his due date. For example, a baby born three months early is, at the actual age of seven months, only four months old according to his corrected age.

**Developmental Age** The age at which a child is functioning (demonstrating specific abilities) based on assessment of the child's skills and comparison of those skills to the age at which they are considered typical. For example, at the chronological age of 36 months, a child might demonstrate the skills of a 30 months-old, and thus said to have a developmental age of 30 months.

*Also known as **Functional Age**.*

**Developmental Delay** (1) Infant or young child's lack of expected progress in cognitive development, physical development (including vision and hearing), communication development, social/emotional development, or adaptive development. (2) For infants and toddlers, the criteria which specify eligibility requirements for Tennessee's Early Intervention System.

**Diagnosed Condition** A physical or mental condition that has a high probability of resulting in developmental delay, e.g., known, obvious, or diagnosable conditions such as sensory losses and severe physical impairments.

**Diagnostic Instruments** Evaluation tools that are used to determine a child's eligibility for early intervention services under Part C of IDEA.

**Disability** (1) A substantially limiting physical or mental impairment which affects basic life activities such as hearing, speaking, seeing, walking, caring for oneself, learning, or working. (2) **Developmental Disability** Any physical or mental condition that begins before the age of 18 years that causes a child to acquire skills at a slower rate than his peers, is expected to continue indefinitely, and impairs the child's ability to function normally in society.

**Early Childhood Specialist** An early childhood special educator, early childhood educator, child development specialist, child psychologist, child life specialist, pediatric therapist, etc. who has experience and training in assessment of infants and toddlers using standardized and criterion-referenced instruments as well as clinical judgment.

**Early Intervention Services** Required services under Part C of IDEA that are provided to infants and toddlers with disabilities in order to achieve the outcomes identified on the IFSP. The early intervention services are designed to meet the developmental needs of the child and the family related to enhancing the child's development. Required services include:

Assistive technology	Occupational therapy
Audiology	Physical therapy
Family training, counseling, home visits	Psychological
Health	Social work
Medical (for diagnostic purposes only)	Special instruction
Nursing	Speech/language pathology
Nutrition	Transportation
	Vision

**Eligible Child** Under Part C of IDEA, an infant or toddler who meets the requirements for eligibility as described in Tennessee's Definition of Developmental Delay.

**Evaluation** The procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility for early intervention services consistent with Tennessee's Definition of Developmental Delay. This includes determining the status of the child in each of the following developmental areas: (a) cognitive development, (b) physical development [including vision and hearing], (c) communication development, (d) social/emotional development, and (e) adaptive development. "Evaluation" is a term often used interchangeably with "assessment." However, in the context of Part C of IDEA, "evaluation" refers to procedures used to determine a child's eligibility for early intervention services.

**Family-Centered** The recognition that the family is the constant in a child's life and that service systems and personnel must support, respect, encourage, and enhance the strength and competence of the family.

**Family-Focused Professional** A social worker, family therapist, school counselor, school psychologist, etc. who has experience and training in assessment of families and with infants/toddlers who have delays using standardized instruments, checklists, and interviews as well as informed clinical opinion.

**Fetus** The developing unborn child from the end of the embryonic stage (the 12<sup>th</sup> week of pregnancy) until the date of delivery.

**Full-Term** Infant born between 38<sup>th</sup> and 42<sup>nd</sup> weeks of gestation.

**Gestational Age** The estimated age of a fetus expressed in weeks, calculated from the first day of the last normal menstrual period.

**Gram** The basic unit of weight in the metric system. There are 28 grams in one ounce.

**Health Professional** Includes pediatric nurse/nurse practitioner, pediatrician, developmental pediatrician, pediatric resident, family practice physician, family practice resident, pediatric physician's assistant, speech therapist, physical therapist, occupational therapist, etc.

**Hydrocephalus** The increased accumulation of cerebrospinal fluid within the ventricles of the brain.

**Hyperbilirubinemia** In certain pathological conditions in which excessive destruction of red blood cells occurs, or in which there is interference with bile excretion, the amount of bilirubin is increased in blood. In newborns with erthroblastosis fetalis and greatly elevated bilirubin, exchange transfusion may be required.

**Hypoglycemia** A condition in which the glucose in the blood is abnormally low.

**Hypotension** Low blood pressure.

**Hypotonia** Decreased muscle tone.

**Hypoventilation** Reduced rate and depth of breathing.

**Hypoxemia** Insufficient oxygenation of the blood.

**Hypoxic Ischemic Encephalopathy** Brain dysfunction caused by impaired blood flow and oxygen delivery, usually during labor and delivery.

**Inborn Errors of Metabolism** A group of inherited metabolic diseases caused by the absence or deficiency of specific enzymes essential to the metabolism of basic substances such as amino acids, carbohydrates, vitamins, or essential trace elements. Examples include phenylketonuria and hereditary fructose intolerance.

**Individualized Family Service Plan (IFSP)** A written plan, developed in accordance

with Part C of IDEA, for providing early intervention and other services to an eligible child and the child's family.

**Individuals with Disabilities Education Act (IDEA) (PL 101-476)** Federal legislation that provides funds for special education and related services for children with disabilities from birth through the age of twenty-one years. Funds are provided through the Infants and Toddlers Program (known as Part C of IDEA) for services to children birth through age two and through the Preschool Program (known as Part B-Section 619 of IDEA) for services to children three through five years of age.

**Interagency Agreement** Policies and procedures for collaboration among agencies are written in a formal document primarily when contracts are involved. The written document outlines how collaboration between two or more agencies will occur.

**Intrauterine Growth Retardation** Delayed fetal growth, usually defined as weight less than the 10<sup>th</sup> percentile for gestation.

**Intraventricular Hemorrhage** Abnormal internal or external discharge of blood within a ventricle.

**Kilogram** Unit of weight of the metric system that equals 1000 grams or 2.2 pounds.

**Meningitis** Infection of the membranes of the spinal cord or brain.

**Memorandum of Understanding (MOU)** There are many types of MOUs. It is an agreement to "work towards working together." The terms and language can be much looser than for a contract or an Interagency Agreement.

**Microcephaly** Head circumference more than two standard deviations below the average size.

**Myelination** The process of acquiring a myelin sheath that is a fatlike substance around the axons of certain nerves.

**Neonatal** 28 days from the date of birth.

**Neonatal Intensive Care Unit (NICU)** Hospital facility that provides life support to newborns with complex medical needs.

**Neonatologist** Specialist in pediatrics specifically trained to care for newborns.

**Nurse Practitioner** A licensed nurse who has completed additional graduate training that allows him/her to perform examinations and procedures under the supervision of a physician.

**Pediatrician** Doctor who specializes in the development, growth, and diseases of childhood.

**Perinatal** Describing the period from 28 weeks gestation to one week following delivery.

**Premature Infant** A baby born before the 37<sup>th</sup> completed week of pregnancy.

**Primary Care Physician** A generalist physician who provides definitive care to the undifferentiated patient at the point of first contact and takes continuing responsibility for

providing the patient's care. Such a physician must be specifically trained to provide primary care services (American Academy of Family Physicians).

**Qualified Personnel** Early intervention services must be provided by qualified personnel, who have met State approved or recognized certification licensing, registration, or other comparable requirements that apply to the area in which the person is providing early intervention services.

**Referral** Actions that guide children and families toward and assist them to access available resources for help, treatment, or information.

**Registered Nurse** Any person who holds a license to practice professional nursing under chapter 78, ò 16; T.C.A., ò 63-744.

**Service Coordination** The activities carried out by a service coordinator, in accordance with Part C of IDEA, to assist and enable an eligible child and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under Tennessee's Early Intervention System.

**Service Coordinator** An individual appointed by a public agency or selected by IFSP participants and designated in the IFSP to carry out service coordination activities.

**Social Worker** Licensed social worker "means a person who holds a license authorizing the practice of social work, which includes social services to individuals, groups or communities in any one or more of the fields of social casework, social group work, community organization for social welfare, social work research, social welfare administration or social work education." Ch. 225, §20/3(9).

**Tennessee's Early Intervention System (TEIS)** The entity established by the Tennessee Department of Education (lead agency) to be responsible for the planning, implementation, supervision, monitoring, and technical assistance for the state-wide early intervention system for infants and toddlers with disabilities in accordance with Part C of IDEA.

**Thrombosis** The formation of a blood clot.

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## Appendix A Tennessee's Definition of Developmental Delay

Eligibility for early intervention services depends on the presence of developmental delay or the presence of a condition likely to result in developmental delay. Any child from birth through age two is eligible if he or she meets Tennessee's eligibility requirements as stated in Tennessee's Definition of Developmental Delay:

The term "infant and toddlers with disabilities" means a child, from birth through age two, who is eligible for early intervention services because he or she:

**Part A:** Is experiencing developmental delays, as measured and verified by appropriate diagnostic instruments, administered by qualified examiners, indicating that the child is functioning at least 25% below his or her chronological age in two or more of the following development areas:

- Cognitive development;
- Physical development, including fine motor, gross motor, and sensory development, (vision and hearing);
- Communication development;
- Social/emotional development;
- Adaptive development

OR

Is functioning at least 40% below his or her chronological age in one of the areas listed above;

OR

**Part B:** Has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, i.e., known, obvious, or diagnosable conditions such as sensory losses and severe physical impairments. Examples include, but are not limited to:

- Hearing loss, which can be verified or estimated to be significant as indicated through an audiological evaluation;
- Visual loss, which can be verified or estimated to be significant; for example, cataracts, glaucoma, strabismus, albinism, myopia, retinopathy of prematurity, or dysfunction of the visual cortex;
- Neurological, muscular, or orthopedic impairment which prevents the development of other skills; for example, congenital dislocation of the hip, spina bifida, cerebral palsy, rheumatoid arthritis, autism, epilepsy;
- Organic conditions or syndromes which have known significant consequences; for example, tuberous sclerosis, hydrocephalus, muscular dystrophy, fetal alcohol syndrome;
- Chromosomal, metabolic, or endocrine abnormalities; for example, Down Syndrome, Klinefelter Syndrome, Turner Syndrome, hypothyroidism; and
- Prematurity as specified by Tennessee's Early Intervention System.

## **Appendix B Documentation of Eligibility**

Infants and toddlers who meet the criteria for Tennessee's Definition of Developmental Delay based on the Premature Infant Criteria are eligible for early intervention services. A service coordinator in the Tennessee's Early Intervention System (TEIS) district office documents an infant or toddler's eligibility by completing the following forms:

1. Professional Verification of Current Diagnosis      To verify a child's eligibility under Part B of Tennessee's Definition of Developmental Delay. Instead of the Professional Verification of Current Diagnosis form, documentation of diagnosis with qualified professional's signature may be used in substitution of this form.
  
2. Eligibility Documentation                                      To document how an infant/toddler's eligibility for early intervention services was established.
  
3. Review of Pertinent Records                                      To provide a summary of information related to the child's current health and medical history.

# Eligibility Documentation

CHILD'S NAME: \_\_\_\_\_

DATE OF BIRTH: \_\_\_\_\_

## PART A of Definition (Attach Appropriate Documentation)

Diagnostic Instrument: \_\_\_\_\_ % delay in \_\_\_\_\_ development

\_\_\_\_\_ % delay in \_\_\_\_\_ development

Administered by: \_\_\_\_\_

Agency: \_\_\_\_\_

Date Administered: \_\_\_\_\_

Diagnostic Instrument: \_\_\_\_\_ % delay in \_\_\_\_\_ development

\_\_\_\_\_ % delay in \_\_\_\_\_ development

Administered by: \_\_\_\_\_

Agency: \_\_\_\_\_

Date Administered: \_\_\_\_\_

## PART B of Definition (Attach Appropriate Documentation)

Diagnosed Condition: \_\_\_\_\_

Name and Title of Professional Verifying Condition: \_\_\_\_\_

Date Verified: \_\_\_\_\_

## INFORMED CLINICAL OPINION (Attach Appropriate Documentation)

Rationale for Informed Clinical Opinion: \_\_\_\_\_

Team Members:

Family: \_\_\_\_\_

TEIS Coordinator: \_\_\_\_\_

Evaluator: \_\_\_\_\_

Other: \_\_\_\_\_

Date Consensus Reached: \_\_\_\_\_

Eligibility for services is based on the following: (1) A review of an appropriate evaluation as described in Part "A" of the Definition; or (2) The verification of a diagnosed condition as described in Part "B" of the Definition; or (3) The attached written documentation for Informed Clinical Opinion.

Multidisciplinary Team Members (not signatures)

Position

Date

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Eligibility Documentation

### Instructions

#### Required or Equivalent Form

**Purpose:** To document how an infant/toddler's eligibility for early intervention services was established. CFR 303.16; CFR 303.322

**Method:** Prior to the initial IFSP meeting, the incoming service coordinator completes this form which is based on information provided by the multidisciplinary team members who were involved in the evaluation and assessment activities.

If the child's identification/eligibility status is being changed due to a re-evaluation, then the designated service coordinator completes this form prior to the annual IFSP meeting or IFSP review.

#### Instructions:

##### Part A of Definition

1. Enter the two diagnostic instruments that were used to determine eligibility for Part A of the Definition.
2. Enter the percentage of delay as measured by the instruments and the areas of development in which the delay occurs.
3. Enter the name of the professionals who administered the instruments.
4. Enter the dates that the instruments were administered.
5. Attach copies of the evaluation reports. (There must be at least two reports.)

##### Part B of Definition

1. Enter the diagnosed physical or mental condition.
2. Enter the name and title of the professional verifying the diagnosis.
3. Enter the date the diagnosed condition was verified.
4. Attach copy of the Professional Verification of Current Diagnosis.

##### Informed Clinical Opinion (ICO)

1. State the rationale for establishing eligibility based on Informed Clinical Opinion.
2. Enter the names of the Team members who are determining the eligibility based on (ICO).
3. Enter the date that the consensus for eligibility was reached.
4. Attach the Informed Clinical Opinion Summary.

List the **Multidisciplinary Team Members** that represent two or more disciplines or professions that were involved in the evaluation to establish eligibility.

## Professional Verification of Current Diagnosis

Child's name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Child's address: \_\_\_\_\_

Parent/guardian names: \_\_\_\_\_

---

Tennessee's Early Intervention System coordinates needed services for infants and toddlers with disabilities and their families.

Eligibility is being considered for the above named child because he/she has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

In order to establish eligibility, verification by an involved physician or other qualified professional is required.

---

Please complete this form for the child indicated above and return to:

Service coordinator: \_\_\_\_\_ Agency: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

---

I hereby certify that the above named child has been diagnosed as having: \_\_\_\_\_

(Please state name of condition or diagnosis, which could result in developmental delay).

---

\_\_\_\_\_  
Signature of physician or other professional

\_\_\_\_\_  
Please print or type name of physician or other professional

\_\_\_\_\_  
Title

\_\_\_\_\_  
Address

\_\_\_\_\_  
Date of signature

\_\_\_\_\_  
City, State, Zip

# Professional Verification of Current Diagnosis

## Instructions

### Required or Equivalent Form

**Purpose:** To verify a child's eligibility under Part B of Tennessee's Definition of Developmental Delay. CFR 303.16 (a) (2); CFR 303.322 (b) (1)

The term "infant and toddlers with disabilities" means a child, from birth through age two, who is eligible for early intervention services because he/she:

**Part B:**

has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, i.e., known, obvious, or diagnosable conditions such as sensory losses and severe physical impairments. Examples include, but are not limited to:

- Hearing loss which can be verified or estimated to be significant as indicated through an audiological evaluation;
- Visual loss, which can be verified or estimated to be significant; for example, cataracts, glaucoma, strabismus, albinism, myopia, retinopathy of prematurity, or dysfunction of the visual cortex;
- Neurological, muscular or orthopedic impairment which prevents the development of other skills; for example, congenital dislocation of the hip, spina bifida, cerebral palsy, rheumatoid arthritis, autism, epilepsy;
- Organic conditions or syndromes which have known significant consequences; for example, tuberous sclerosis, hydrocephalus, muscular dystrophy, fetal alcohol syndrome;
- Chromosomal, metabolic, or endocrine abnormalities; for example, Down Syndrome, Klinefelter Syndrome, Turner Syndrome, hypothyroidism; and
- Prematurity, as specified by Tennessee's Early Intervention System Premature Infant Criteria.

**Method:** The service coordinator should send this form to the involved physician or other professional who is qualified to establish eligibility by Part B of Tennessee's Definition of Developmental Delay. The physician or professional should sign the form to verify that the diagnosis is current and correct.

### Instructions:

1. Complete the identifying information regarding the child.
2. Complete the information regarding the service coordinator and indicate where this form needs to be sent.
3. The physician or qualified professional states the name of the diagnosed condition or the service coordinator may state the name of the diagnosed condition if it is known.
4. The physician or qualified professional signs this form verifying diagnosis and prints or types his/her name, title, address, and the date of signature.

# Review of Pertinent Records

Child's name: \_\_\_\_\_

Date this form completed: \_\_\_\_\_

This form completed by: \_\_\_\_\_

Agency: \_\_\_\_\_

---

Medical history and health summary: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Source of information, including medical records reviewed:

Source: \_\_\_\_\_ Date of record: \_\_\_\_\_

---

Information regarding vision:

\_\_\_\_\_

\_\_\_\_\_

Source: \_\_\_\_\_ Date: \_\_\_\_\_

Source: \_\_\_\_\_ Date: \_\_\_\_\_

---

Information regarding hearing:

\_\_\_\_\_

\_\_\_\_\_

Source: \_\_\_\_\_ Date: \_\_\_\_\_

Source: \_\_\_\_\_ Date: \_\_\_\_\_

---

Developmental screening summary (if applicable): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Screening completed by: \_\_\_\_\_

Date screening completed: \_\_\_\_\_

# Review of Pertinent Records

## Instructions

### Required or Equivalent Form

**Purpose:** To provide a summary of information related to the child's current health status and medical history. CFR 303.322 (c) (3) (i)

**Method:** Prior to determining eligibility, and as a component of the evaluation and assessment, this form should be completed by the service coordinator after gathering information regarding the child's health status and medical history, including vision and hearing status.

### Instructions:

1. Summarize pertinent health status and medical history from information that was obtained from medical records and other sources.
2. Document the source of information including the medical records reviewed. Identify the date that the medical record was completed.
3. Provide a short description of vision status, including the source and the date that the evaluation, assessment, and/or screening was completed.
4. Provide a short description of hearing status, including the source and the date that the evaluation, assessment, and/or screening were completed.
5. If a developmental screening has been completed prior to this review, summarize the results. Identify who completed the screening and the date the screening was completed.

## Appendix C Description of Assessment Tools

### **Assessment, Evaluation, and Programming System for Infants and Children (AEPS)**

- **Assessment type:** A criterion-referenced developmental tool to assess and evaluate the skills and abilities of infants and young children who are at risk and who have disabilities.
- **Ages:** The developmental age range of test items is 1 month to 3 years. It has been used with infants and children who are medically at risk (e.g., premature and low birth weight) or environmentally at risk.
- **Domains:** Six broad curricular areas called domains are included: fine motor, gross motor, adaptive, cognitive, social-communication and social.
- **Scores:** Data Recording Forms (one form for each domain) for professionals; parents can complete parallel assessment with the Family Report forms. Functional skills and abilities are measured. Scoring based on rating of child's performance on the items specified in the criteria. A percent score is obtained based on total score is possible.
- **User qualifications:** For use by direct service personnel (e.g., interventionists, home visitors) and specialists (e.g., communication specialists, occupational therapists, physical therapists, psychologists).
- **Ordering information:** Paul H. Brookes Publishing Co.  
Post Office Box 10624  
Baltimore, MD 21285-0624  
1-800-638-3775  
Fax: 1-410-337-8539  
www.brookespublishing.com

### **Battelle Developmental Inventory (BDI)**

- **Assessment type:** Norm based/curriculum compatible; used for diagnosis, evaluation; and program development
- **Ages:** Birth to age 8
- **Domains:** Personal-Social, Adaptive, Motor, Communication, and Cognitive
- **Scores:** Domain scores (developmental age, z-score, developmental rate, normal curve equivalent, percentile), standard scores, and age equivalents
- **User qualifications:** It is primarily designed for use by infant, preschool, and primary teachers as well as special educators. Speech pathologists, psychologists, adaptive physical education specialists, and

clinical diagnosticians will also find the BDI effective in measuring the functional abilities in young children. Although appropriate for nonpsychologists, supervised practice in administration for preschoolers with disabilities is critical. (Bagnato, 1997).

- Ordering information: Riverside Publishing  
425 Spring Lake Drive  
Itasca, IL 60143-2079  
800/323-9540 (orders)  
800/767-8420 (general business)  
www.riverpub.com

### **Carolina Curriculum for Infants and Toddlers with Special Needs (CCITSN)**

- Assessment type: Curriculum embedded
- Ages: Designed for children who have mild to severe special needs and who function in the birth to 24 months developmental range.
- Domains: Cognition, communication, social/adaptive, fine motor skills, and gross motor skills
- Scores: Assessment Log and Developmental Progress Charts for children from birth to 2 years and for children from 12 months to 3 years
- User qualifications: Knowledge of principles of learning in and assessment of children with special needs; can be used by professionals, assistants, and parents with some professional support.

Ordering information: Paul H. Brookes Publishing Co.  
Post Office Box 10624  
Baltimore, MD 21285-0624  
1-800-638-3775  
Fax: 1-410-337-8539  
www.brookespublishing.com

### **Hawaii Early Learning Profile (HELP)**

- Assessment type: A curriculum embedded tool used for developmental assessment, intervention planning, and instruction with infants and toddlers and their families
- Ages: Designed for infants with special needs from birth to 3 years
- Domains: Six developmental domains: gross motor, fine motor, cognition, expressive language, social and emotional development, and adaptive
- Scores: HELP charts and HELP Checklists are used to identify current mastery of skills, needs, and objectives. They are used for recording and visually tracking progress of the child.

- User qualifications: Knowledge of and experience with infants and toddlers with disabilities; consultation with other professionals is encouraged.
- Ordering information: VORT Corporation  
Post Office Box 60880  
Palo Alto, CA 94306  
1-412-322-8282  
1-888-757-VORT  
www.vort.com

### **Neonatal Behavioral Assessment Scale (NBAS)**

- Assessment type: Process-oriented assessment
- Ages: Newborns up to two months. As of 1996, NBAS is not appropriate for assessing a stressed or premature infant. Recommending that a set of 10 qualifiers be added to the NBAS to make it useful with at risk and immature neonates (Brazelton, 1996).
- Domains: Items are grouped into six behavioral clusters (habituation, autonomic, motor, state organization, state regulation, and social-interactive behavior) and one reflex cluster.
- Scores: Scores on the behavioral scale are rated on a 9-point scale; reflex is scored on a 3-point scale. Performance on each dimension can be described as optimal, normal, or inadequate.
- User qualifications: Prospective examiners should have an adequate background in infant development in order to interpret the infant's behavior. Certification as a NBAS examiner involves both self-training and reliability training.
- Ordering information: Riverside Publishing  
425 Spring Lake Drive  
Itaska, IL 60143-2079  
800/323-9540 (orders)  
800/767-8420 (general business)  
www.riverpub.com

### **Test of Sensory Functions in Infants (TSFI)**

- Assessment type: A criterion-referenced tool designed to provide an overall measure of sensory processing and reactivity in infants with regulatory disorders
- Ages: 4 to 18 months
- Domains: Five domains of sensory processing and reactivity: reactivity to tactile deep pressure, adaptive motor functions, visual-motor integration, ocular-motor control, and reactivity to vestibular stimulation.

- Scores: Criterion-referenced
- User qualifications: Not specified
- Ordering information: Western Psychological Services  
12031 Wilshire Blvd.  
Los Angeles, CA 90025-1251  
800/648-8857  
FAX: 310/478-7838

## Appendix D

# Neonatal Intensive Care Units

**Baptist Hospital**  
2000 Church Street  
Nashville, TN 37236  
1-615-329-7762

**Baptist Memorial Hospital**  
899 Madison Avenue  
Memphis, TN 38146  
1-901-227-2727

**Baptist Memorial Hospital East**  
6019 Walnut Grove Rd.  
Memphis, TN 38120

**Baroness Erlanger Hospital/T.C. Thompson's  
Children's Hospital \***  
975 E. 3<sup>rd</sup> Street  
Chattanooga, TN 37403  
1-423-778-7000

**Centennial Medical Center  
NICU at The Women's Hospital**  
2300 Patterson Street  
Nashville, TN 37203  
1-615-342-1000

**East Ridge Hospital**  
941 Spring Creek Road  
Chattanooga, TN 37412  
1-423-855-3688

**East Tennessee Children's Hospital**  
2018 Clinch Avenue  
Knoxville, TN 37916  
1-423-541-8000

**Hendersonville Hospital**  
355 New Shackle Island Road  
Hendersonville, TN 37075  
1-615-264-2000

**Jackson-Madison County  
General Hospital**  
708 West Forest Avenue  
Jackson, TN 38301  
1-901-425-5000

**Johnson City Medical Center Hospital \***  
400 State of Franklin Road  
Johnson City, TN 37604  
1-423-431-6343

**Methodist Health Care-NICU @ Central**  
1265 Union Avenue  
Memphis, TN 38104  
1-901-726-7000

**Metro-Nashville General Hospital**  
1818 Albion Street  
Nashville, TN 37208  
1-615-341-4000

**Middle Tennessee Medical Center Special Care  
Nursery**  
410 N. Highland Avenue  
Murfreesboro, TN 37130  
1-615-849-4100

**Regional Medical Center at Memphis (The Med)\***  
853 Jefferson Avenue, Room 201  
Memphis, TN 38103  
1-901-765-1811

**St. Mary's NICU-Women's Pavilion**  
900 East Oak Hill Avenue  
Knoxville, TN 37917-5432  
1-423-545-8000

**Summit Medical Center-Special Nursery**  
5655 Frist Blvd  
Hermitage, TN 37076  
1-615-316-3000

**University of Tennessee  
Medical Center at Knoxville\***  
1924 Alcoa Highway  
Knoxville, TN 37920  
1-423-544-9000

**Vanderbilt University Medical Center/ Vanderbilt  
Children's Hospital\***  
1211 22<sup>nd</sup> Avenue South  
Nashville, TN 37232  
1-615-322-5000

**Wellmont Holston Valley Hospital and Medical  
Center**  
130 West Ravine, Box 238  
Kingsport, TN 37660  
1-423-224-6096

\* Regional Perinatal Centers

Appendix E



**“Tomorrow’s Success Begins Today”**

**Tennessee's Early Intervention System  
Committee on Infant Prematurity**

**Report on Responses to  
NICU Parent Questionnaire**

**January 2001**

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## Summary

Families of children in Tennessee referred to state services due to low birth weight (1200 grams) between April 1999 and April 2000 were surveyed. Family input was sought to assist members of the Tennessee's Early Intervention System (TEIS) Committee on Infant Prematurity in their charge. Results indicate a need for continued and improved collaboration between TEIS and neonatal intensive care units in their combined efforts to address the medical and developmental needs of premature infants and their families.

## Background

TEIS is a statewide program, under Tennessee's Department of Education, designed to provide information, support, referral, and funding for early intervention services that are federally mandated under the Individuals with Disabilities Education Act (IDEA). Services to infants and toddlers (birth through two years of age) are authorized under Part C of the IDEA. In the spring of 1999, TEIS initiated a committee composed of members from health and education disciplines across the state. The mission of this committee was to establish eligibility criteria for premature infants and to develop best practice guidelines for serving eligible premature infants. Neonatal intensive care units (NICU) across the state were surveyed in regard to their referral process with the early intervention system. Additionally, members of the committee sought parental input via a questionnaire. Family input was believed to be essential in developing best practice guidelines for service delivery. The results of this parent questionnaire are the subject of this report.

Elsa Nownes interviewed mothers of children with special needs enrolled in TEIS. Nownes noted that significant changes have occurred in delivery of early intervention services because of changes in best practice beliefs on the part of professionals and changes within the laws. In her investigation, Nownes points out:

Mothers from this study indicated that they received both instrumental and emotional support from their service coordinators. Concerns about the early intervention system included a shortage of information about the system, a shortage of resources, insufficient support from other professionals, and concerns about specific early intervention policies.

Mothers from the Nownes study made recommendations for addressing the above concerns. According to Nownes:

Mothers indicated that they wanted to be more knowledgeable about all the services within the early intervention system that they may need to use in the future. Mothers indicated that they wanted their children's physicians to communicate better with them. Mothers also indicated that they did not like the process for the Individualized Family Service Plan. (Elsa Nownes, doctoral dissertation, presented December 1998 to the University of Tennessee, Knoxville)

Members of the TEIS Committee on Infant Prematurity recognized the concerns and needs expressed by mothers in the Nownes study. Additionally, TEIS is committed to a family-centered approach to families.

A family-centered philosophy in early intervention places major emphasis on supporting and strengthening the family as part of developing the Individualized Family Service Plan (IFSP). The family-centered principles are rooted in the belief that family-centered early intervention seeks to build on and promote the strengths and competencies present in families. The guiding principles of the IFSP are that the family is the child's greatest resource and that the child's needs are closely tied to the needs of the family. The best way to meet the child's special needs is to support and build on the individual strengths of the family. (TEIS *Individualized Family Service Plan Manual*)

In a study comparing families' and professionals' perceptions of the implementation of the family-centered philosophy, different types of barriers were identified.

Families found barriers in dealing with medical professionals who did not refer to early intervention or did not communicate clearly. Professionals found diversity among families to be a barrier for them. (Ladmer, 1994)

Since a family-centered philosophy is the underlying basis for Part C legislation of the IDEA, committee members chose to query families regarding public awareness and child find, evaluation and assessment, service coordination, required early intervention services, and the Individualized Family Service Plan (IFSP). The information acquired would be used to assist the committee in developing family-centered guidelines for referral and service delivery to infants with prematurity.

## **Purpose**

The purpose of the parent questionnaire was to seek and utilize parental expertise in developing procedures for readily identifying infants who may be eligible for early intervention (EI) services. Further, family-centered guidelines for service delivery would be, in part, based on input from families completing the questionnaire.

## **Method**

Three hundred and seventy-six questionnaires were sent to Tennessee families that were referred to state services due to low birth weight (1200 grams) during the time of April 1999-April 2000. Forty questionnaires were returned. Results are reported based on data from these forty questionnaires, unless otherwise indicated. When less than forty responses were received for a given item, the number answering (n) was noted. Respondents included thirty-nine parents and one grandparent. The average length of pregnancy was reported as twenty-six weeks, with a range from twenty-three to thirty-four weeks.

# Results

## Public Awareness and Child Find

Families were queried regarding when and how they were referred to TEIS. They were questioned regarding their opinion of the appropriateness of the referral as well.

When families were asked if they saw TEIS brochures in the NICU, twenty-three percent indicated they did, while seventy-seven percent indicated they did not. Respondents reporting that they saw TEIS brochures in the NICU follow-up clinic reported almost identical responses, with twenty-five percent reporting that brochures were present and seventy-five percent reporting they were not.

Families were further queried with the following results:

### How did you learn about TEIS?

Informed by	Percentage of respondents (n=37)
Hospital or hospital related service	32%
TEIS	27%
Another parent	18%
Support service (SSI, pediatrician, etc.)	23%

### When did you learn about TEIS?

In relation to discharge from NICU	Percentage of respondents (n=17)
Prior to discharge	70%
At the time of or shortly after discharge	18%
One or more months after discharge	12%

### Were you and your infant referred to TEIS while you were in the NICU?

Yes	43%
No	57%

### Were you and your infant referred to TEIS while you were enrolled in the NICU follow-up clinic?

	(n=39)
Yes	15%
No	85%

A percentage of those indicating that they were not referred while enrolled in the NICU follow-up clinic obviously were already referred while in the NICU. Of twenty families responding when asked if they felt the referral to TEIS was necessary, ninety-five percent indicated that it was. Fifteen families offered an explanation for the above response. Reasons given by the families who indicated that they did feel the referral to TEIS was necessary included a desire to receive all available assistance and appreciation for the safety net of services available if needed. Of the families who indicated they did not feel the referral was necessary, one stated that a direct service provider was able to address their needs, and the other indicated that they were not yet aware of their child's special needs.

Of twenty-five families who reported being referred to TEIS, eighty percent indicated that their first contact with TEIS was in their home. Twelve percent of those responding indicated that first contact was in the NICU, while eight percent indicated that first contact was by some other means. Of the twenty-five families responding, eighty-four percent indicated they understood why they were being referred to TEIS and they agreed to the referral. Of twenty-five families responding, eighty-eight percent indicated they felt their referral to TEIS was made at the appropriate time, and ninety-two percent indicated that after referral they were contacted by TEIS in a timely manner.

## Evaluations and Assessments

Eighty percent of families responding (n=39) indicated that no one discussed having a multidisciplinary evaluation in order to determine eligibility for early intervention services while their child was in the NICU. Similar results were reported while the child was in the NICU follow-up clinic (79%, n=34). When asked if their child received a multidisciplinary evaluation for eligibility for services through TEIS, fifty-three percent of families indicated they had (n=38).

Responses are summarized below to questions regarding when the first multidisciplinary evaluation for determining eligibility for early intervention services took place and the child's age at the time:

### When did your child receive the first multidisciplinary evaluation to determine eligibility for TEIS?

In relation to discharge from the NICU	Percentage of respondents (n=20)
During hospital stay in the NICU	20%
After discharge from the NICU	80%

### How old was your child at the time of this evaluation?

Months	Percentage of respondents (n=17)
1-2	23%
3-4	35%
5-6	18%
7-8	12%
9-10	6%
11-12	6%

Of sixteen families responding when asked how they would change the evaluation experience to better suit their family, eighty-one percent indicated they were pleased with the process and would make no changes. Nineteen percent of families did suggest changes. Their concerns related to the excessive volume of paper work and the time required to accommodate multiple evaluators.

Families were asked when they would prefer to be informed of the evaluation for early intervention services. Of the thirty-two families responding, sixty-nine percent would like to be informed while they are in the NICU, while twenty-eight percent preferred to wait until after hospital discharge. Three percent of families indicated a choice other than the above.

Families were asked if they wished their child had received a multidisciplinary evaluation for eligibility for early intervention services. Of the families responding to this item (n=24), eighty-three percent indicated they would have liked to have this evaluation. Of twenty-seven families responding, forty-eight percent indicated they would have liked for this evaluation to take place while their child was in the NICU and fifty-two percent preferred after hospital discharge.

## **Service Coordination**

Sixty-eight percent of those responding (n=34) indicated that they have a service coordinator who has the responsibility to assist their family in receiving early intervention services through TEIS. Of those responding (n=29), thirty-four percent said they first met the TEIS service coordinator while their child was in the NICU. Sixty-two percent indicated they first met their service coordinator after hospital discharge, with four percent indicating another response.

Families were asked if they would have chosen to have a TEIS service coordinator while they were in the NICU. Of thirty-one families responding, sixty-eight percent indicated that they would. When respondents indicated they preferred not to have a service coordinator while in the NICU, the primary reason given was related to a desire to have time to adjust to all that occurred since the infant's birth. Families expressed that this would give them time to adapt, settle in, and bond with their infant.

## Services

Under Part C of the IDEA, states are federally mandated to offer specific early intervention services to families of eligible infants and toddlers. Families were asked to indicate the services that they received while in the NICU and the NICU follow-up clinic. Families were queried as to whether or not they would have liked to receive additional early intervention services while they were in the NICU. Of thirty-two families responding, forty-four percent indicated they would, while fifty-six percent indicated they would not.

<b>Service</b>	<b>Percentage of respondents receiving service in NICU (n=40)</b>	<b>Percentage of respondents receiving service in NICU follow-up clinic (n=40)</b>	<b>Percentage of respondents who indicated they would have benefited from this service while in the NICU (n=10)</b>
Assistive technology	15%	8%	10%
Audiology	28%	18%	10%
Family training, counseling, home visits	35%	20%	80%
Health (necessary to help the child benefit from EI services)	28%	10%	10%
Medical (for diagnosis and evaluation to determine need for EI services)	25%	18%	30%
Nursing (as a component of EI services)	20%	8%	20%
Nutrition	25%	18%	20%
Occupational therapy	25%	23%	10%
Physical therapy	33%	25%	10%
Psychological	10%	3%	0%
Service coordination	18%	13%	10%
Social work	45%	10%	20%
Special instruction (information, skills, and support that enhance the child's development)	23%	13%	40%
Speech-language	15%	10%	0%
Transportation (to EI services)	10%	5%	10%
Vision	45%	15%	10%

## **Individualized Family Service Plan (IFSP)**

An IFSP is both a process and a form, required by law, that describes the outcomes (goals or changes) that the family hopes to accomplish over the next twelve (or less) months for their child and their family. An IFSP, developed by the family and other multidisciplinary team members, provides the framework for meeting the unique needs of the child and family. (TEIS *Individualized Family Service Plan Manual*)

Of thirty-nine families responding, forty-six percent indicated that they have had an IFSP. When asked when their first IFSP was developed, seventeen families responded. Of those, ninety-four percent indicated this took place after discharge from the hospital.

Families were asked to indicate if they think an IFSP would have been beneficial to their family while they were in the NICU. Of twenty-nine families responding, fifty-nine percent felt it would have been useful. Families indicating that an IFSP would not have benefited them while they were in the NICU expressed that other issues such as the health concerns of the child, loss of employment, financial worries, etc. were of primary importance at that time. Additionally, they expressed that they did not yet know if their child would have special needs requiring developmental intervention.

The primary reason given by those indicating that an IFSP would have been helpful was that this process would assist them in understanding their child's developmental strengths and needs at a time when they were eager for information. They also indicated this process would provide knowledge of service options allowing them to better prepare to meet their child's needs. It was stated that having an IFSP while in the NICU would give parents the opportunity to consult with physicians regarding how their child's needs could best be met.

Finally, when invited to offer any recommendations regarding TEIS and the NICU, twenty-two responses were given. Of those, eight families offered kind words of praise and appreciation for the assistance given to their child and family by both TEIS and the NICU. One suggestion was made that NICUs refer all babies born at thirty weeks gestation or less to TEIS. One family preferred that TEIS contact them while they were in the NICU, while another family preferred that information only be given while in the NICU, with follow-up contact after discharge. The suggestion was made that TEIS service coordinators strive to reduce the use of technical lingo, and more frequent contact with service coordinators was desired. Several families felt more awareness and information about TEIS should be made available.

## Discussion

In regard to public awareness and child find, the need for information about TEIS in the NICU and in the NICU follow-up clinic was well documented. TEIS should strive to supply brochures and information on a regular basis. Public awareness activities should also be conducted with NICU personnel.

The majority of parents learn about TEIS while they are in the NICU and are first contacted by a service coordinator in their home, following discharge from the hospital. Parents responding to the questionnaire understood why they were referred to TEIS, agreed to the referral, desired the referral, and felt that referrals were made at the appropriate time.

In regard to evaluations and assessment, it is clear that most parents do not report a discussion about multidisciplinary evaluations for eligibility for early intervention services while they are in the NICU. Most parents would like to have this information. One concern related to this questionnaire may be a misunderstanding of terminology. Part C of the IDEA defines multidisciplinary as:

The involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities and development of the IFSP. (TEIS *Individualized Family Service Plan Manual*)

Evaluation and assessment for programming are terms with specific meanings as well.

Evaluation means the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility for early intervention services consistent with Tennessee's Definition of Developmental Delay. This includes determining the child's status in each of the following developmental areas: (a) cognitive development, (b) physical development (including vision and hearing), (c) communication development, (d) social/emotional development, and (e) adaptive skills. "Evaluation" is a term often used interchangeably with "assessment". However, in the context of Part C of the IDEA, "evaluation" refers to procedures used to determine a child's eligibility for early intervention services. (TEIS *Individualized Family Service Plan Manual*)

Infants and toddlers who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay are not in need of an evaluation for eligibility. Their diagnosed condition qualifies them for early intervention services. They then receive an assessment for programming.

Assessment includes the initial and ongoing procedures used by qualified personnel throughout the period of a child's eligibility under Part C to identify:

- i. The child's unique strengths and needs and the services appropriate to meet those needs;
- ii. The resources, priorities, and concerns of the family related to the development of the child;
- iii. The supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability; and
- iv. The current and potential activities, relationships, routines, and culture that constitute the child's natural environment.

(TEIS *Individualized Family Service Plan Manual*)

Since conditions associated with prematurity might qualify a child for early intervention services, that child would receive an assessment for programming rather than a multidisciplinary evaluation. Obviously, this distinction can be confusing to parents and professionals alike, possibly influencing responses to the questionnaire.

Eighty-one percent of families responding when asked what changes they would make to the evaluation process indicated a high level of satisfaction with the present approach and that they would make no changes. This reinforces the family-centered approach being used by TEIS.

When asked, the majority (68%) of parents indicated that they would like to have a service coordinator from TEIS while they are in the NICU. However, only thirty-four percent of families responding to a survey question about this indicated that they met their service coordinator for the first time while in the NICU. Clearly NICU personnel are in a position to recognize when it is appropriate to involve the TEIS service coordinator. Service coordinators must approach families gently with information and options so that families can receive as much or as little as they desire in regard to service coordination. Service coordinators can provide support to families while their child is in the NICU and can assure them that resources and funding sources are available following discharge. A referral shortly before discharge seems to be the best course of action. NICU personnel can facilitate the initial contact with the TEIS service coordinator by helping that coordinator know when to contact parents and by locating a place in the hospital where families and service coordinators can meet together if desired. Including TEIS service coordinators in discharge planning would also be beneficial.

Even though definitions of early intervention services required to be made available under the IDEA were presented in the questionnaire, it can be very difficult to distinguish these services from hospital related services. However, results of the questionnaire do indicate that a high number of families are interested in receiving family training, counseling, and home visits, as well as special instruction. This supports statements by families desiring information about typical child development and what they might expect in regard to the development of the premature infant.

Almost all families who responded to the item regarding when the IFSP was first developed for their family indicated that they participated in the IFSP process after their child was discharged from the NICU. Families seem to be equally conflicted regarding whether an IFSP would be useful to them in the NICU or if they preferred to participate in this process following hospital discharge. For this reason, it is clear that a family-centered approach is essential. While the majority of families want information and referral to TEIS while in the NICU, development of the IFSP and delivery of services will be dependent on the individual needs of the child and family.

Results presented in this report were collected from a small sample across the state of Tennessee. The length of the survey may have negatively impacted a family's willingness to complete the questionnaire. Presumably, families of premature infants have their own unique stressors that may have also contributed to the low level of response. Therefore, one must use caution in making broad assumptions based on the survey results. Having acknowledged that, it must also be stated that all families and all babies are unique. There is value to be gained from each individual experience.

TEIS adheres to a family-centered philosophy. Just as infants and toddlers with special needs require individualized plans of service, families require an individualized approach to address their unique needs.

It is clear from the survey that families want information from the start. TEIS and neonatal intensive care units across the state should be commended for their present collaboration, while acknowledging that we can always improve. Once a referral is made to TEIS and the service coordinator meets with the family, then the informed family will lead the way. Some families want services as soon as possible, while others have concerns that must take precedence for the time being. The family, team members, and the TEIS service coordinator should be able to determine a plan of action that suits the individual needs of a given family.

Input received from families via this survey only serves to strengthen the professional's ability to work cooperatively and effectively with families. Appreciation is expressed to the families who participated in this effort.

### **Works Cited**

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## Appendix F

# Individuals with Disabilities Education Act (IDEA)

The federal law that authorizes early intervention and special education programs for infants and children with disabilities is called the Individuals with Disabilities Education Act (IDEA). Until recently, the law was known as the Education of the Handicapped Act (EHA). In 1990, the title of the law was changed and the term “handicapped” was replaced with the term “disability”. IDEA contains several parts. Two parts, Part B and Part C, authorize programs for infants and young children with disabilities and their families. Tennessee’s Early Intervention System (TEIS) falls under Part C of IDEA, which is also called “Infants and Toddlers with Disabilities”. In Part C, the term “infants and toddlers” refers to children from birth through age two years, until the third birthday. (Beckman & Boyes, 1993)

The Individuals with Disabilities Education Act (IDEA), Part C, states the following:

- (a) The Congress finds that there is an urgent and substantial need-
  - (1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
  - (2) to reduce the educational cost to our society, including our Nation’s schools, by minimizing the need for special education and related services after infants and toddlers reach school age;
  - (3) to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independent living in society;
  - (4) to enhance the capacity of families to meet the special needs of their infant and toddlers with disabilities; and
  - (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations.
- (b) It is the policy of the United States to provide financial assistance to States-
  - (1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides for early intervention services for infants and toddlers with disabilities and their families;
  - (2) to facilitate the coordination of payment for early intervention services from Federal, State, local and private sources (including public and private insurance coverage);
  - (3) to enhance their capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families; and
  - (4) to encourage States to expand opportunities for children under 3 years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services.

The statewide comprehensive systems under IDEA, Part C, are intended to address the needs of infants and toddlers who are experiencing developmental delays or a diagnosed physical or mental condition with a high probability of an associated developmental delay in one or more of the following areas: cognitive development, physical development (including vision and hearing), communication development, social or emotional development, and adaptive development. Children who meet these criteria are eligible to receive early intervention services that are developmental in nature and satisfy the following conditions:

- Services must be provided under public supervision;
- Services must be provided at no cost, except where federal and state laws allow;

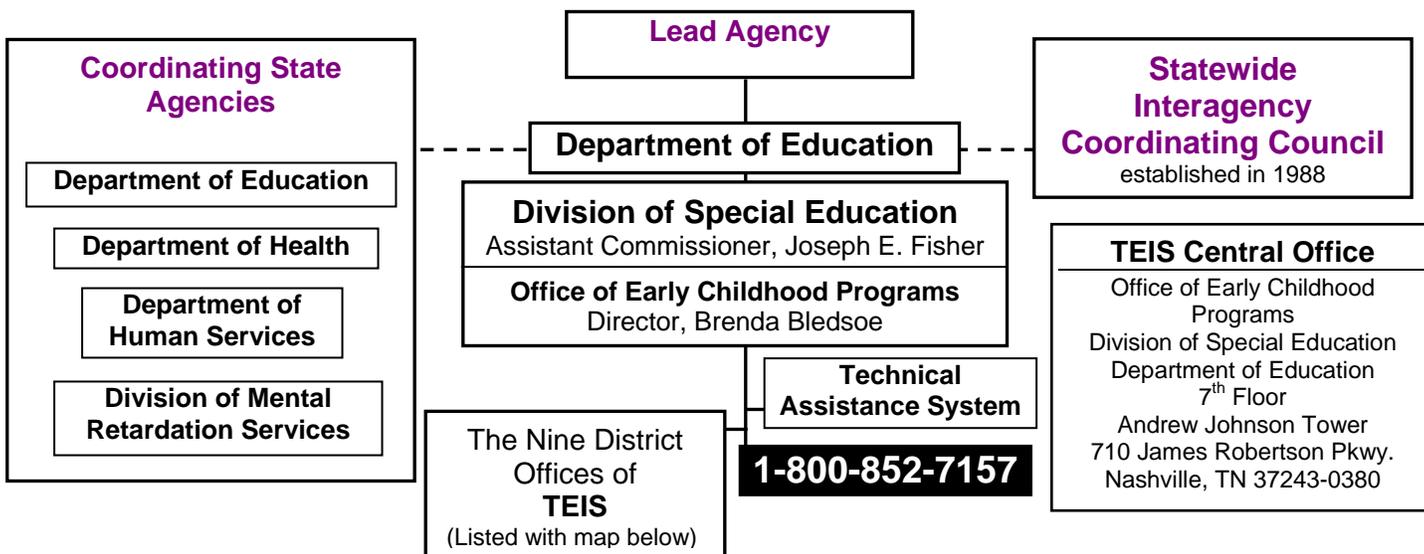
- Services must be designated to meet the developmental needs of the child across all five delay areas;
- Services must meet state standards, as well as federal standards;
- Services must be provided by qualified personnel; and
- Services must be delivered in conformity with the Individualized Family Service Plan (IFSP).

Early intervention services provided by statewide systems must be individualized to meet children's needs and characteristic of the particular state. There are fourteen minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs.

1. Definition of developmentally delayed
2. Central directory
3. Public awareness program
4. Comprehensive child find system
5. Evaluation, assessment, and nondiscriminatory procedures
6. Individualized family service plans
7. Comprehensive system of personnel development
8. Personnel standards
9. Supervision and monitoring of programs
10. Lead agency procedures for resolving complaints
11. Policies and procedures related to financial matters
12. Interagency agreements; resolution of individual disputes
13. Policy of contracting or otherwise arranging for service
14. Data collection

Tennessee's Early Intervention System (TEIS) operates within the large framework created by IDEA. In 1989, TEIS was authorized in Tennessee through state legislation, Tennessee Public Chapter No 248, House Bill No. 1113. Tennessee has developed a statewide, comprehensive, multidisciplinary, inter-agency system that provides early intervention services for infants and toddlers with disabilities and their families. Detailed guidelines, under the auspices of IDEA, have been developed to ensure identification, delivery of services, and protection of parental rights. The goal of the early intervention system is to expand opportunities for children less than three years of age who are exhibiting significant developmental delays or have an established condition that has a high probability of resulting in developmental delays.

Under the governing federal law (IDEA) each state must designate a lead agency that will be responsible for the administration of the available early intervention funds under Part C of IDEA. In Tennessee, the early intervention system has been established with Tennessee's Department of Education, making it the lead agency. Policies and procedures for carrying out the delivery of services within the early intervention system originate within the Division of Special Education in the Department of Education. Since its creation in 1989, the early intervention system in Tennessee has made great strides in its efforts to best serve infants and toddlers with disabilities and their families (Tennessee, 2000).



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 vnance@utm.edu

**5. Greater Nashville**

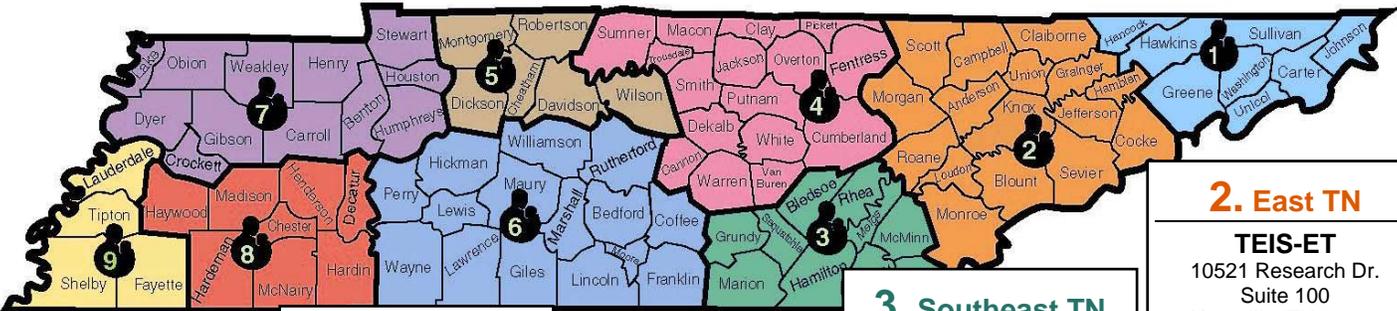
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# Tennessee's Early Intervention System Organizational Flow Chart

**Local Coordinating Councils (One per district)**

