

# *Working Together*

HEALTH SERVICES FOR CHILDREN IN FOSTER CARE

*NYS Office of Children and Family Services*

## *Appendix D*

# Protocol: Children in Foster Care Who Participate in the Early Intervention Program

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PROTOCOL  
CHILDREN IN FOSTER CARE WHO PARTICIPATE IN THE EARLY INTERVENTION PROGRAM

**PROTOCOL**

**CHILDREN IN FOSTER CARE WHO PARTICIPATE  
IN THE  
EARLY INTERVENTION PROGRAM**

This protocol was developed by NYS Department of Health Early Intervention Program in collaboration with NYS Office of Children and Family Services.

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## **PURPOSE**

Children ages birth through three years may be eligible for participation in the Early Intervention Program (EIP) because they are experiencing developmental delays or disabilities. Some of these children will be in foster care. The purpose of this Protocol is to describe the procedures and steps that staff in local early intervention programs and child welfare systems should follow to coordinate the services they provide to children who are in foster care and may also be eligible for the early intervention services. The Protocol follows a child from referral to the Early Intervention Program through discharge; explains the requirements of the early intervention system and the child welfare system; and, addresses when staff from both systems should coordinate, collaborate and share information.

## **DESCRIPTION OF THE EARLY INTERVENTION PROGRAM**

### **Background**

Article 25, Title II-A of the Public Health Law establishes the Early Intervention Program (EIP), a voluntary program offering a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead agency for the Early Intervention Program. The EIP is administered locally in each of the 57 counties and New York City. An Early Intervention Official/Designee (EIO/D) in each municipality is responsible for identifying eligible children residing within the municipality and ensuring that early intervention services contained in the family's individualized family service plan (IFSP) are delivered (see **Appendix A** for definitions of key words and phrases).

The statewide EIP offers therapeutic and support services to infants and toddlers with disabilities and their families. The following services can be included in the IFSP: assistive technology devices and services, family training and counseling, home visits, parent support groups, special instruction, speech-language pathology and audiology, occupational therapy, physical therapy, psychological services, service coordination, nursing services, nutritional services, social work services, vision services and transportation/related costs necessary to participate in early intervention services and health services. The EIP only provides health services necessary to enable a child to benefit from other early intervention services while the child is receiving these services.

### **Eligibility**

To be eligible for early intervention services a child must be under three years of age and have a disability or developmental delay.

A disability means a child has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay (e.g., Down syndrome, autism, cerebral palsy) (see **Appendix B** - Children's Eligibility Status Based on Diagnosed Conditions with High Probability of Developmental Delay).

A developmental delay means that a child has not attained developmental milestones expected for the child's chronological age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional and adaptive.

A developmental delay for purposes of the EIP is a developmental delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures and/or instruments and documented as:

- a twelve month delay in one functional area; or
- a 33% delay in one functional area or a 25% delay in two areas; or
- if appropriate standardized instruments are administered during the evaluation, a score of at least 2.0 standard deviations below the mean in one functional area or a score of at least 1.5 standard deviations below the mean in each of two functional areas.

### **Major Provisions of the Early Intervention Program**

Public Health Law which governs the EIP requires provision of:

- initial and ongoing service coordination services for eligible children and families;
- a multidisciplinary evaluation provided to determine eligibility, including an opportunity to engage in a family assessment process;
- an individualized family service plan (IFSP) for eligible children and their families;
- delivery of early intervention services in the IFSP that are provided at no cost to families; and,
- delivery of services in natural environments with typical age peers, to the maximum extent appropriate. Natural environments are settings that are natural or normal for the child's age peers who have no disability, including the home, a relative's home when care is delivered by the relative, child care setting, or other community setting in which children without disabilities participate.

A Governor-appointed State Early Intervention Coordinating Council (EICC) advises and assists the NYS Department of Health regarding policy and systems issues related to the EIP. Each municipality has a Local Early Intervention Coordinating Council (LEICC) to advise and assist with local implementation and quality improvement activities.

### **Brief Description of the Early Intervention Steps**

#### Referral to the EIP

Early Intervention Officials/Designees (EIO/D) are responsible for ensuring that infants and toddlers that are at risk are identified, screened and tracked for appropriate periodic development, using all available state, local and community resources to accomplish this objective.

Primary referral sources are responsible for identifying and referring infants and toddlers suspected of having a disability or at risk for a disability to the EIO or public health official, as designated by the municipality, unless the parent objects to the referral (see **Appendix C** for a listing of Required Early Intervention Primary Referral Sources). Under NYS Public Health Law, Department of Social Services staff are identified as a Primary Referral Source and are responsible for referring children under three years of age who they suspect of having or being at risk of a developmental delay (see **Appendix G** - Referral of Children at Risk).

**It is important to note that the EIP and foster care system have a different definition of children at risk** (see Section on “Terminology”).

### EIP Evaluation

#### *Children Suspected of Disability*

The Early Intervention Official/Designee must designate an initial service coordinator for children who are referred due to being suspected of having a disability (e.g., developmental delay or a diagnosed condition with a high probability of developmental delay). The initial service coordinator provides the family with information about the EIP; informs the family of their rights and safeguards; reviews the list of evaluators; obtains insurance/Medicaid information and other relevant information from the family; and assists the family in identifying and applying for Medicaid, Child Health Plus and other public benefit programs for which the family may be eligible. A multidisciplinary evaluation, which may include a screening, is conducted with the child and family to determine if the child is eligible for early intervention services and to gather information about the family’s and child’s strengths and needs that will assist in decisions about services.

#### *Children with an Established Diagnosed Condition*

A child who has an established diagnosed condition with a high probability of delay at the time of referral is eligible for early intervention services based upon the diagnosis. However, s/he must participate in a multidisciplinary evaluation to confirm eligibility for the Program and prepare for the Individualized Family Service Plan meeting.

### Development of an Individualized Family Service Plan (IFSP)

If the child is eligible for early intervention services, an IFSP meeting must occur within 45 days of the receipt of the child’s referral. At the IFSP meeting, the IFSP team, which includes the parent, initial service coordinator, evaluator, EIO/D, and any other person, such as the child’s primary health care provider or child care provider, who the parent or the initial service coordinator invite, with the parent’s consent, identify desired outcomes and specify early intervention services to be provided in a written IFSP. Once the parent and the EIO/D agree to the IFSP, the parent selects an ongoing service coordinator who is responsible for ensuring that services provided to the child are consistent with the IFSP. The child and family will receive the services agreed to in the IFSP. The IFSP is reviewed at six-month intervals and evaluated

annually by the EIO/D, service coordinator, the parent and service providers to determine if desired outcomes have been achieved, and if services need to be modified.

### Transition of Children from the EIP at Age Three

Eligibility for early intervention services ends at a child's third birthday, unless the child will be transitioning to preschool special education services. A child who will be transitioning to preschool special education services may be eligible to stay in the EIP past the child's third birthday, depending upon the child's birth date.

### **Parent Participation in the Early Intervention Program**

The EIP is a voluntary program. Parents have the option to participate in the program, and they may accept or reject some or all early intervention services for the child. However, if there is a court order requiring a child to participate in the EIP, the parent(s) must comply with the terms of the court order, and the EIO/D must ensure the provision of evaluation or other EI services according to the terms of the court order. Even when there is a court order, the parent(s) should be engaged in the evaluation and provision of services to the maximum extent possible.

Where the parent is unavailable and/or availability is limited due to life circumstances such as the parent residing far from the child; the parent residing in an institution; the parent's location is unknown; or, the parent does not want to be involved or is prohibited from decision-making regarding the child, the EIO/D is responsible for determining the need for a surrogate parent for the eligible child. The appointment of a surrogate will not be necessary in all instances. To determine whether a surrogate parent is needed with regard to a child in foster care, the EIO/D, in consultation with the local Commissioner of Social Services or designee, should make reasonable efforts to determine if the parent is available.

If the parent is available, the EIO/D, service coordinator and the LDSS Foster Care Caseworker should take steps to encourage the parent to be involved in the IFSP process and in service delivery. If the parent is determined to be unavailable or parental rights have been terminated or voluntarily surrendered, the EIO/D is responsible for appointing the surrogate parent for the purpose of the EIP. The EIO/D and the LDSS Foster Care Caseworker should consult with each other prior to the appointment of a surrogate parent for the child. A parent can voluntarily appoint a surrogate parent upon written consent. A surrogate parent has all the rights and responsibilities under the EIP necessary to enable the child to fully participate in the EIP. This can be a very complex issue and is discussed more fully in the section "Appointing a Surrogate Parent in the Early Intervention Program."

### **Service Coordination in the Early Intervention Program**

Service Coordination must be provided to all children referred to an EIO/D as suspected of having a disability. Since infants and toddlers with disabilities require a comprehensive array of services that may be provided by multiple agencies or individuals, federal and state laws require the provision of a service coordinator who is responsible for ensuring communication,

collaboration, and coordination among providers of service to eligible children and families. The service coordinator must be approved by the EIP to provide EI service coordination services.

There are two types of service coordinators in the EIP - an initial service coordinator and ongoing service coordinator. The EIO/D assigns the initial service coordinator upon the referral of a child thought to be an eligible child. The initial service coordinator has primary responsibility for ensuring that the parent is informed about the EIP and their rights under the Program; securing the essential information and consent from the parent necessary for participation in early intervention services; and assisting parents in selecting an evaluator and obtaining a screening and/or multidisciplinary evaluation for the child. At the initial IFSP meeting, the parent selects the ongoing service coordinator from a list of approved service coordinators who are under contract with the municipality in which the eligible child resides. The ongoing service coordinator is responsible for coordinating the services provided by various service providers included in the IFSP; working with the family to enhance the child's development; monitoring the child's progress to identify changes needed in the plan; preparing and coordinating the six-month and annual review of the family service plan; and facilitating the child's transition out of the EIP.

## **THE CHILD WELFARE SYSTEM**

### **Background**

Article 6 of the Social Services Law establishes the child welfare system and describes procedures for placement of children into foster care. Article 10 of the Family Court Act sets forth the standards and procedures for child protective proceedings, including the placement of abused or neglected children in the custody of a relative or other suitable person or the Commissioner of Social Services. The Social Services Law also sets forth provisions for the voluntary placement of children into foster care. In the 57 counties outside of New York City and the St. Regis Mohawk Tribe, Local Departments of Social Services (LDSS) administer child welfare services, including child protective, preventive, foster care and adoption services.

Children placed by Family Court order in the custody of the local Commissioner of Social Services or the St. Regis Mohawk Tribe are considered to be in foster care. In New York City, the Administration for Children's Services (ACS) administers the child welfare system and its services. Children in foster care in New York City are placed in the custody of the Commissioner of the ACS. The rules governing the actual care of and services available to foster care children are the same, whether placement occurs in New York City or the rest of the state.

New York State's child welfare policy primarily focuses upon the safety of the child. When a child must be removed from the parent's home, the least restrictive setting must be provided, and work must begin immediately on a permanency plan for the child. Many children are placed in foster care as a result of a child protective proceeding. Children are also placed into foster care on a voluntary basis. Generally, a child placed in foster care is placed in the care and custody of

the local commissioner of social services. The child's parent retains legal rights and responsibilities for the child.

In cases where the parent voluntarily surrenders guardianship and custody, or where the Family Court terminates the parents' rights, the parent no longer has guardianship and custody of the child. The EIP would consider such children who are in the guardianship and custody of the Local Commissioner of Social Services as "wards of the state." For all children in foster care, a case manager and case planner, are assigned and is responsible for foster care case planning while the child is in foster care status. For purposes of this protocol, the case manager and the case planner will be referred to as the "LDSS Foster Care Caseworker."

## **Foster Care Services**

### Foster Care Placement

Districts must place foster care children in foster homes, agency operated foster boarding homes, group homes or institutions directly or through an approved authorized agency. While in some cases, the Family Court has the authority to order placement of a child into a particular foster care arrangement, the legal care and custody of the child remain with the LDSS/ACS. The local district with legal custody of the child retains fiscal responsibility for the child.

Foster family homes are private homes in which a single person or family is certified or approved to provide care to a specified number of children at any given time. Young children are usually placed in foster family homes. Foster family homes include approved relative homes, commonly called "kinship" placements. Early intervention professionals should understand that in the case of informal kinship arrangements, where the LDSS Commissioner does not have legal custody of the child, the adult relative with whom the child is residing does not always have legal responsibility for the child. These children may not be known to the LDSS Commissioner and do not have a formal relationship with the LDSS (i.e., they will not have a caseworker). Under these circumstances, when no legal guardian has been appointed, the Early Intervention Official must determine the need for a surrogate parent (see the section - "Appointing a Surrogate Parent in the EIP").

Children in foster care may also be placed in congregate care settings including:

- institutions, which provide care for 13 or more children;
- group residences, which are institutional settings with a maximum of 25 children;
- group homes, which are family like settings serving not less than seven or more than 12 children; and,
- agency operated boarding homes, which are family-like settings serving not more than six children unless they are part of a larger sibling group.

### Medical Evaluation

All children in foster care are required to receive a basic medical evaluation within 30 days of the child entering foster care, with follow-up assessments, evaluations and/or treatment occurring

as recommended by the physician. While the evaluation should include a developmental assessment, it does not replace the multidisciplinary evaluation required by the EIP. However, with parental consent the results of the evaluation should be made available to the EIP multidisciplinary evaluation team. It is important for the initial service coordinator to work with the LDSS caseworker and the child's parents to determine what evaluations have occurred prior to the early intervention referral and to assure that the child is under the care of a primary care physician.

### Permanency Planning

Policies related to placement in the least restrictive setting, permanency planning and other standards for the provision of foster care services are the same throughout the state. Permanency planning for children, i.e., supporting the process of reunification with the natural family, as long as it can be established that it is consistent with the safety of the child, is a key policy in the foster care system. There is a clear intent for foster care to be a short-term, interim step in a child's journey to permanency. Achievement of permanency objectives for children in care, in accordance with a child's needs for emotional security and healthy development, must be considered in any decision-making regarding the child.

### **Role of LDSS Foster Care Case Workers**

The LDSS will assign a case manager to each child in foster care. The case manager is responsible for placement of the child and for authorizing the provision of preventive services that are included in a written child and family service plan. The case manager develops permanency plans. In some districts the case manager is also responsible for coordination and evaluation of provision of those preventive services needed by a child and his/her family to prevent disruption of the family and to facilitate the child's reunification with his/her natural family. In districts that use foster care agencies, a case planner assigned from the agency may be responsible for this function. Even when the contract agency case manager is the day-to-day contact and planner for the child, the contract agency is required to have the case manager sign off on all decisions/changes regarding the child's care.

For purposes of this protocol, the case manager and the case planner will be referred to as the "LDSS Foster Care Caseworker."

## **COMMUNICATION AND COLLABORATION BETWEEN THE EARLY INTERVENTION PROGRAM AND THE CHILD WELFARE SYSTEM**

### **System Focus**

While both the EIP and the foster care system are concerned with the well being of children and families and are complementary to each other, each system has its unique focus and responsibilities. The child welfare system provides services to children whose families, for a variety of reasons, cannot provide adequately for them. The focus of the foster care system is to provide a stable, safe home environment for the child; to see that health, education and other necessary services are available to the child; and, to provide the child with a safe permanent

living arrangement. The early intervention system provides many different types of early intervention services to infants and toddlers who meet the eligible criteria for the program. Many children participating in the child welfare system can benefit from, and will be found eligible for, early intervention services, and, conversely, some children in the early intervention system will need the services of the child welfare system. It is important that professionals involved in both systems understand how and when their roles and responsibilities intersect, if children served by each system are to receive the full benefits and supports these systems have to offer.

### **Communication Between Professionals in the Two Systems**

Professionals working in each system must communicate and work together when involved with the same child and family. While meeting their own program responsibilities to facilitate early intervention services and family supports, it is critical that EIP staff understand decisions made and information conveyed by child welfare system professionals. Child welfare professionals, in turn, should understand early intervention requirements and utilize early intervention services to enhance the development of a child and the capacity of his/her caregivers when a child is developmentally compromised.

#### EIP Professional's Role

It is important for the EIP to inform the LDSS Foster Care Caseworker about the child's early intervention eligibility status, service plan, and progress, so that the LDSS can more effectively carry out its responsibilities for general management of the child's foster care program, taking into consideration what is happening to the child while s/he is receiving early intervention services.

#### LDSS Foster Care Professional's Role

It is important for the LDSS Foster Care Caseworker to keep the EIO/D and EI service coordinator apprised about the child's placement, location, health/medical status and permanency plan status. Ongoing awareness of the child's whereabouts and custodial situation will allow the local EIP to develop and implement a supportive and appropriate service plan, and to appropriately claim and receive reimbursement from the State Program. This collaborative relationship will enable EIP staff to be a resource to child welfare professionals when a child in foster care is identified as having a disability or is suspected of having a delay in development, and/or when a parent or foster care parent has concerns about coping with a child with a disability.

### **Terminology**

Professionals in both systems should also understand the terminology used by each system. Key terms that should be understood as they are used in one or both systems are as follows:

### *Child At Risk*

The EIP defines a child at risk as one who is at risk for developmental delays or disability. In the foster care system, a child at risk is one who experiences parental neglect or abuse, is at risk of out-of-home placement or other compromising circumstances. It is important for LDSS and other staff working in the foster care system to understand that a child who is at risk and is placed in the foster care system may not be eligible for early intervention services. A child must meet the state's EIP eligibility criteria as previously described to receive early intervention services.

### *Least Restrictive Setting/Natural Environment*

In the child welfare system, the term "least restrictive setting" means placing a child in the most home-like setting in which the child can be maintained safely and receive all services specified in their service plan. This setting should permit the child to retain contact with persons, groups, and institutions with whom they have been involved, or to which the child will be discharged. This is similar, but not the same, as the EIP concept of natural environments. Natural environments are defined by the EIP as settings that are natural or normal for the child's age peers who have no disability, including the home, a relative's home when care is delivered by the relative, child care setting, or other community settings in which children without disabilities participate. Early intervention services are provided in conformance with an IFSP and, to the maximum extent appropriate, in natural environments.

## **MANDATED REPORTING**

Children are reported to the child welfare system when the parent's action or inaction causes the child harm or places the child at imminent risk of harm. This will warrant a report to the State Central Register of Child Abuse and Maltreatment (1-800-342-3720) for investigation. Two districts, Onondaga (315) 422-9701 and Monroe (585) 461-5690, maintain their own child abuse and maltreatment hotline numbers. Title 6 of Social Services Law on Child Protective Services (Sections 413 and 414) describes which professions are required to report cases of suspected child abuse maltreatment to the State Central Register of Child Abuse and Maltreatment for investigation (see **Appendix D** -Mandated Reporters of Child Abuse and Maltreatment). Early Intervention Providers who are Child Abuse and Maltreatment Mandated Reporters under the Social Services Law may call the Mandated Reporters' hotline number (1-800-635-1522). Any person who is not a mandated reporter may make a report if they believe there is reasonable cause to suspect child abuse or maltreatment.

Reporting of child abuse or maltreatment is a serious step and should not to be taken lightly. Each child/family's situation should be considered very carefully prior to making a report. There may be situations that EIP professionals encounter that require a report to the State Central Register of Child Abuse and Maltreatment (see **Appendix F** for definition of Child Abuse and Maltreatment). In addition, there may be circumstances under which a parent's refusal to participate in EI services may need to be considered in the decisions of making a report of child abuse or maltreatment (see **Appendix E** for the description of Medical Neglect).

Under the EIP, a service coordinator may be a mandated reporter by virtue of his/her professional license or certification and of their seeing the family in that status. EIO/Ds and agencies that employ service coordinators must establish policies to ensure that service coordinators inform a responsible party about any suspected cases of child abuse and maltreatment.

Since not all early intervention service providers are mandated reporters by virtue of their professional licenses or certification, EI agencies and individuals who are under contract to provide early intervention services should develop procedures for non-mandated reporters related to the reporting of child abuse and maltreatment.

### **APPOINTING A SURROGATE PARENT IN THE EARLY INTERVENTION PROGRAM**

EIP regulations require the EIO/D to determine if a child needs a surrogate parent and to appoint a qualified surrogate parent to assume the responsibilities of a parent and to represent the child in all matters related to participation in the EIP when:

- A child has no available parent or person acting in place of a parent that can be identified.
- The whereabouts of the parent(s) is unknown.
- The child is a Ward of the State, (a foster care child in the custody and guardianship of the local commissioner of social services).

The role of a surrogate parent is to make decisions regarding the child within the early intervention system. The surrogate parent is afforded the same rights and responsibilities as accorded to the parent and represents the child in all matters related to: screening, evaluation, IFSP development and implementation, provision of early intervention service, periodic review of IFSP services and due process procedures. A surrogate parent has access to all early intervention records concerning the child and due process rights related to those records.

When a child is in the foster care system and is referred to the EIP, the EIO/D should consult with the social service district to determine whether parental rights have been terminated or voluntarily surrendered, and whether the parent is available. This also provides an opportunity to share information; identify any potential barrier to parental consent and participation; and to determine the need for, and, as appropriate, identify a suitable surrogate parent.

Where the parent is unavailable and/or availability is limited due to life circumstances such as the parent residing far from the child; the parent residing in an institution; the parent's location is unknown; or, the parent does not want to be involved or is prohibited from decision-making regarding the child, the EIO/D is responsible for determining the need for a surrogate parent for the eligible child. The appointment of a surrogate will not be necessary in all instances. To determine whether a surrogate parent is needed, the EIO/D in consultation with the local Commissioner of Social Services or designee, should make reasonable efforts to determine if the parent is available. If the parent is available, the EIO/D, service coordinator and the LDSS Foster Care Caseworker should take steps to encourage the parent to be involved in the IFSP process and in service delivery. If the parent is determined to be unavailable or parental rights

have been terminated or voluntarily surrendered, the EIO/D is responsible for appointing the surrogate parent for the purpose of the EIP. The EIO/D and the LDSS Foster Care Caseworker should consult with each other prior to the appointment of a surrogate parent for the child. A parent can voluntarily appoint a surrogate parent upon written consent.

**The final decision regarding the appointment of a qualified surrogate parent rests with the EIO/D.** The appointment or removal of a surrogate parent can occur at any time while the child is in the early intervention system. The EIO/D can appoint a different surrogate parent when appropriate and necessary (e.g., the surrogate parent is no longer willing and able to participate, or the surrogate parent fails to fulfill his or her duties). The EIO/D can remove the appointment of the surrogate parent, if it is determined that the parent is able to fully participate in the EIP.

The EIO is responsible for selecting a surrogate parent who is qualified and willing to serve and who:

- has no interest that conflicts with the interests of the child;
- has knowledge and skills that ensure adequate representation of the child;
- if available and appropriate, is a relative who has an ongoing relationship with the child; or,
- is a foster parent with whom the child resides.

Under the federal Individuals with Disabilities Education Act (IDEA), the surrogate parent may not be an employee of any state agency (e.g., LDSS Commissioner, caseworker, case manager, case planner) or a person or employee of a person providing early intervention services (EIO/D, EI service coordinator) to the child. While the LDSS Commissioner can consent to medical, dental and hospital services for children who are in the commissioner's custody, IDEA specifically excludes state officials from acting as a surrogate parent in the EIP.

#### Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Available to Participate

Unless parental rights have been terminated or surrendered, the EIP and foster care systems should take steps to encourage the parent to be involved in the IFSP process and in early intervention services delivery. This protocol assumes the parent will continue to be actively involved in the EIP process, if the parent is available. However, even when the parent is available, there may be circumstances under which the EIO/D determines that it is in the best interest of the child to appoint a surrogate. The EIO/D should consult with LDSS Foster Care Caseworker before appointment of a surrogate parent. If a surrogate is appointed in such a case, the EIP should continue to try to involve the parent.

#### Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Unavailable or Chooses Not to Participate

In some cases, the parent still retains parental rights but is unavailable and/or availability is limited due to life circumstances, including that the parent resides far from their child; the parent resides in an institution; the parent's location is unknown, the parent does not want to be involved, or is prohibited from decision-making regarding the child; or the child is placed in the

care and custody of the local social service commissioner. The LDSS Foster Care caseworker should immediately advise the initial EI Service Coordinator and EIO/D that the parent is absent and cannot participate or chooses not to participate, so that EIO/D may consult with the LDSS and, as appropriate, appoint a surrogate parent for the child. Whenever possible, the EIP should continue to try to involve the parent in early intervention services.

When it is not known if the parent is available, the EIO/D should make at least two contacts (reasonable efforts) at the last known address in order to locate the parent and ascertain his/her willingness to be involved in the EIP, before appointing a surrogate. The attempts at locating the parent can also be accomplished in conjunction with LDSS.

Parental Rights Terminated or Voluntarily Surrendered

When parental rights have been terminated or voluntary surrender of guardianship and custody has occurred, the EIO/D must appoint a surrogate parent for any eligible or potentially eligible child.

**The EIO should designate the foster care parent or an available relative as the *surrogate parent* for the EIP whenever possible and appropriate.**

The New York State Office of Children and Family Services letter dated 5/27/99 to the local Commissioners of Social Services provides clarification on the authority of local social services districts in regard to foster children who are participating in the EIP (see **Appendix I** - Office of Children and Family Services Commissioner Letter).

**FINANCIAL RESPONSIBILITY**

Nearly all foster care children are eligible for Medicaid. However, some foster care children will retain private commercial insurance. The LDSS is responsible for determining the child's eligibility for Medicaid, and for pursuing third party (private commercial health insurance) coverage where appropriate.

**Early Intervention Program**

As with all other children in the EIP, the municipality is responsible for claiming Medicaid or commercial insurance prior to submitting any claims to the State. When children in foster care are placed outside of their county of residence the following fiscal responsibilities apply:

- The municipality of residence (the municipality in which a child or child's family lived at the time the local social service district assumed responsibility or custody of the child) is financially responsible for the local contribution of the approved cost of early intervention services.

- The municipality of current location (the municipality in which a child currently resides) is responsible for delivering early intervention services to the child and implementing the child/family's IFSP. The municipality of current location may be different from the municipality where the child or his/her family resided at the time a social services district assumed responsibility for the placement of the child. The municipality of current location receives 100% reimbursement from the State, which is offset by the local contribution due. The municipality of residence is financially responsible for the local contribution of the approved cost of early intervention.

### **Foster Care Services**

The LDSS that assumed custody retains financial responsibility for the foster care services provided to the child.

The LDSS will have information regarding the child's Medicaid and commercial insurance and should share this information with the municipal EIP. The municipal early intervention initial service coordinator should obtain all relevant Medicaid and commercial insurance from the LDSS Foster Care Caseworker.

## **Protocol for Interaction Between EIP and Local Districts of Social Services**

The following Foster Care Protocol identifies main procedures and steps that should occur within the Early Intervention System. However, it should be noted that this Protocol is not an inclusive list of all procedures and steps that need to occur. Both LDSS staff and municipal EI staff should be familiar and have sufficient knowledge regarding EI procedures and steps.

The EIP term for ‘parent’ includes, birth, adoptive or person in parental relation to the child. The EIP term ‘in parental relation’ means a child’s legal guardian, standby guardian, custodian or person acting in the place of a parent (grandparent or stepparent). For the purposes of this protocol the term ‘parent’ will be used to represent all of the above-mentioned relationships.

## **CHILD FIND FOR THE EARLY INTERVENTION PROGRAM**

### **RESPONSIBILITIES/ PROCEDURES**

#### **LDSS Foster Care Caseworker:**

- Refers all children in foster care to primary health care providers for a basic medical evaluation health assessment, developmental screen and medical care.
- Is familiar with the New York State Early Intervention Program (EIP).
- Identifies children in foster care with suspected disabilities and developmental delay. This information may be obtained from personal observation, parent/caregiver/foster care information, primary health care provider, and review of health records. A formal evaluation or examination is not necessary for a referral to the EIP.
- Shares basic information about the EIP with families.

#### **EIO/Designee:**

- Maintains a system to identify children with disabilities and developmental delay(s) within the municipality.
- Educates the general public, especially primary referral sources, on how to make referrals to the EIP.
- Ensures primary referral sources, including LDSS Foster Care Caseworkers and health care providers, and foster parents serving children in foster care, understand how to refer children to the EIP.

## **REFERRAL TO THE EARLY INTERVENTION PROGRAM**

### **RESPONSIBILITIES/PROCEDURES**

#### **LDSS Foster Care Caseworker:**

- Functions as a primary referral source (see **Appendix C** - EI Required Primary Referral Sources) under EIP regulations and must refer children at risk (see **Appendix G** – Referral of Children at Risk) who are suspected of having a disability to the municipality where the child resides within two working days of identifying such child. If a child’s parent cannot be reached or located to discuss a referral, and the caseworker believes the child may need early intervention services, a referral should be made to the EIP.
- If feasible prior to referral, explains to the parent the reasons for referral, benefits of services and next steps; or, if feasible, after referral, informs the parent of the referral made by another party.
- If the parent objects to the referral, the LDSS Foster Care Caseworker should document the objection in the Uniform Case Record (UCR) and should follow up in two months to see if the parent will reconsider. The LDSS should refer the child to a primary health provider and work with the primary care provider to conduct developmental surveillance. The health care provider is also a primary referral source to the EIP and should work with the parent to refer the child.
- If circumstances warrant (e.g., child is severely disabled or has significant delays), the LDSS Foster Care Caseworker may alert the LDSS attorney, when necessary and appropriate, for an EIP referral and evaluation and, if appropriate, for services.
- If the child is in the process of being placed in foster care, and there is no firm address for the child, the LDSS Foster Care Caseworker uses the foster care agency or county social services address as the child’s address for referral purposes, until a more permanent address is identified.
- At time of referral, inform the EIO/D if parental rights have been terminated or voluntarily surrendered and if the parent is not available or chooses not to participate.

#### **EIO/Designee:**

- Receives all referrals, including referrals made by foster care parents.
- Promptly designates an initial EI Service Coordinator.
- Promptly informs the LDSS Commissioner or designee when a child in foster care has been referred.
- Determines if a surrogate parent needs to be appointed because a parent is unavailable, or if parental rights have been terminated or voluntarily surrendered.
- Appoints a surrogate parent when appropriate.

<p><b>Recommendations for consideration at the local level</b></p> <ul style="list-style-type: none"><li>• There are state-sponsored early intervention training opportunities for primary referral sources through Department of Health training contracts. Child welfare system managers should be aware of and promote attendance of LDSS staff at this training.</li><li>• Child Welfare System and municipal EIP managers should collaborate and develop a general consent form to share information regarding the child that will meet both system requirements and facilitate sharing of information.</li></ul>
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## **INTAKE INTO THE EARLY INTERVENTION PROGRAM**

### **RESPONSIBILITIES/PROCEDURES**

#### **LDSS Foster Care Caseworker:**

- Receives notification of designation of an initial EI Service Coordinator for the child.
- Facilitates contact with the foster parent or agency providing for the care of the child when not in a foster care home and initial EI Service Coordinator.
- Shares information about previous health/developmental evaluations or other information about the child's development progress with the initial service coordinator.
- Collaborates with the EIO/D, parent/surrogate parent, foster parent when the child and/or family are in apparent immediate need of early intervention services before the evaluation and agrees to the provision of a temporary IFSP - called an interim Individualized Family Service Plan (e.g., a child who has been diagnosed with failure to thrive- the need for nutritional or therapeutic intervention related to feeding).

#### Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Available to Participate

- Assists in arranging a prompt meeting with the initial EI Service Coordinator and the parent.

#### Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Unavailable or Chooses Not to Participate

- Immediately advises the initial EI Service Coordinator and EIO/D that the parent is absent and cannot participate or chooses not to participate, so that EIO/D may consult with the LDSS and, if appropriate, appoint a surrogate parent for the purposes of receiving early intervention services.

#### Parental Rights Terminated or Voluntarily Surrendered

- Immediately advises the EIO/D if parental rights were terminated or if the parent voluntarily relinquished guardianship and custody, and of the terms of any court orders, so that the EIO/D may appoint a surrogate parent for the purposes of the EIP.

#### **EIO/Designee:**

- Promptly contacts the LDSS Foster Care Caseworker to notify him/her of a referral and intake of a foster care child into the EIP and to:
  - verify the residence of the child;
  - determine if parental rights were terminated or if the parent voluntarily surrendered;
  - determine if there are any court orders that must be followed; and,
  - identify and locate the birth parent.
- Obtains parental consent to exchange information about the child with others (general release

or selective release which specifies names or category of those individuals with whom information will be exchanged).

Parental Rights Not Terminated or Voluntarily Surrendered and Parent is Available to Participate

- Notifies the parent and LDSS Foster Care Caseworker of the designation of an initial EI Service Coordinator, in writing. This notification should include the name, address and telephone number of the initial EI Service Coordinator.
- Notifies the initial EI Service Coordinator of the name of the LDSS Foster Care Caseworker and the fact that parental rights were not terminated.
- Makes a reasonable effort to forward a copy of the EIP parent handbook to the parent.
- When necessary and appropriate, collaborates with the LDSS Foster Care Caseworker and agrees to an interim IFSP with the parent and initial EI Service Coordinator.
- Obtains parental consent to obtain and to share EIP information with the child's primary health care provider.
- Obtains parental consent to include the foster care parent in EIP planning and services, as appropriate.
- Explains to the parent the process to voluntarily appoint a surrogate parent through written consent.

Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Unavailable or Chooses Not to Participate

- Immediately consults with the LDSS regarding who could serve as a qualified and appropriate surrogate parent for the child, for the purposes of receiving early intervention services. Makes reasonable efforts to facilitate the parent's involvement in early intervention services. Final decision regarding the appointment of a qualified surrogate parent rests with the EIO/D.
- Appoints a surrogate parent (the foster parent can be the surrogate parent, unless this is not practical, i.e., the child will be moved shortly, etc.) and documents the appointment of the surrogate parent in the child's record.
- Notifies the surrogate parent and LDSS Foster Care Caseworker of the designation of an initial EI Service Coordinator, in writing. This notification should include the name, address and telephone number of the initial EI Service Coordinator.
- Notifies the initial EI Service Coordinator of the surrogate parent and LDSS Foster Care Caseworker.
- Forwards a copy of the EIP parent handbook to the surrogate parent (and, when possible, to the parent) by mail or other suitable means.
- When necessary and appropriate, collaborates with the LDSS Foster Care Caseworker and agrees to an interim IFSP with the surrogate parent and initial EI Service Coordinator.

Parental Rights Terminated or Voluntary Surrendered Steps and procedures are the same as above section "Parental Rights Not Terminated or Voluntarily Surrendered and the Parent is Unavailable or Chooses Not to Participate."

**Initial EI Service Coordinator:**

- Promptly contacts the LDSS Foster Care Caseworker to verify:

- if not known, whether parental rights were terminated (if so, ensures this is documented in the record and advises the EIO/D, if necessary);
- the identity of the parent;
- the child's foster care Medicaid number to bill for early intervention services;
- the child's foster care Medicaid client ID number will be in the following format:
  - NYC: "L", letter, 5 numbers, letter (LX99999X)
  - Rest of State: letter, letter, 5 numbers, letter (XX99999X)

**The Medicaid client ID number should not be confused with a managed care plan number.**

- Documents above information in the service coordination record.
- Notifies the EIO/D of the above information including Medicaid information.
- Documents the appointment of a surrogate parent in the service coordination record.
- Promptly arranges to meet with the parent/surrogate parent to inform them of their rights and entitlements under EIP, and arrange for a multidisciplinary evaluation.
  - Assists the parent/surrogate parent to prepare for the evaluation by explaining the evaluation process, including the opportunity to engage in a voluntary family assessment process with the evaluator.
  - Explains the role of EI Service Coordinator and how it differs and does not replace the role of the LDSS Foster Care Caseworker; impress upon the parent/surrogate parent the need to keep the LDSS Foster Care Caseworker informed about the child's progress in the early intervention system.
  - Obtains parent/surrogate parent consent to share information with the foster parent, if other than the surrogate parent, and consent to the participation of the foster care parent in the planning for and delivery of early intervention services.
  - Assists the parent/surrogate parent to select an evaluator.
- When available, forwards information to the evaluator about previous health/developmental evaluations or other information about the child's health/developmental progress that was obtained from the LDSS Foster Care Caseworker, that may influence the EI evaluation of the child.
- Forwards the consent to share information with the foster parent to the EIO/D.

**Recommendations for consideration at the local level**

EIO/Ds and LDSS should establish policies and procedures to protect the confidentiality of the foster care parent, including the foster care parent's name and address, when there is a safety issue regarding the foster care child and/or foster care parent. Certain information, which may not be released to the parent, should be redacted or removed prior to the release of the Early Intervention Program record to the parent.

## **EARLY INTERVENTION EVALUATION PROCESS**

### **RESPONSIBILITIES/PROCEDURES**

#### **EI Evaluation Provider:**

- Obtains parent/surrogate parent consent to conduct the multidisciplinary evaluation to determine eligibility.
- If the Foster Care Parent has not been assigned as the surrogate parent, obtains consent from the parent/surrogate parent to contact the foster parent to gain a complete picture of the child's daily development and needs for use in the evaluation process.
- Conducts the multidisciplinary evaluation.
- Offers and explains to the parent, surrogate parent and/or foster care parent the opportunity to engage in the voluntary family assessment component of the evaluation that determines resources, priorities, and concerns of the family related to enhancement of the child's development. The parent, surrogate parent, and the foster care parent may all have the opportunity to engage in the family assessment process with the evaluation team. Participation in the family assessment is voluntary on the part of the parent, surrogate parent and/or foster care parent.
- If consent has not been obtained, encourages the parent or surrogate parent to provide parent consent to send the evaluation report to the child's primary health care provider.
- Reviews the results of the evaluation with the parent or surrogate parent.
- Issues an evaluation report and summary in time to conduct the IFSP meeting within 45 days of referral of the child to the EIO/D.
- Sends the evaluation report/summary to the parent/surrogate parent, EIO/D, initial EI Service Coordinator and LDSS Foster Care Caseworker. With consent, forwards a copy of the evaluation report/summary to the child's primary health care provider and to the foster care parent, if the foster parent is not the surrogate parent.

#### **EI (Initial) Service Coordinator:**

- Upon receipt of the evaluation report, reviews the report with the parent/surrogate parent and determines if the parent/surrogate parent understands the report.
- Requests additional diagnostic information regarding the condition of the child, if appropriate, with parent consent and approval of the EIO/D.
- If parent/surrogate parent consent was not obtained to forward the evaluation summary/report to the child's primary health care provider and the foster care parent, makes another attempt to obtain such consent.

#### If child is found ineligible

- Informs the parent/surrogate parent of the right to due process, which includes the right to a second evaluation, to request mediation or an impartial hearing to resolve a dispute regarding eligibility or services, and the right to file a systems complaint if they feel that there has been a violation of EI regulations.

- Informs the parent/surrogate parent of other available services and offers assistance with appropriate referrals to other community services.
- Discusses evaluation results and parent/surrogate parent decision about due process with LDSS Foster Care Caseworker.
- If found ineligible for EI services, but considered “at risk”, the child would be tracked and screened through the EI tracking system for appropriate periodic developmental surveillance.

If child is found eligible

- Informs the parent/surrogate parent about the IFSP meeting and process, including who may attend.
- Informs the parent/surrogate parent about selection of an ongoing EI Service Coordinator at the IFSP meeting and the role of the ongoing EI Service Coordinator.
- Assists the parent, surrogate parent, and/or foster care parent (with parental consent) to prepare for the meeting to develop the individualized family service plan, including helping them understand the child’s evaluation(s) and identifying their priorities, resources, concerns related to their child’s development.
- Informs the LDSS Foster Care Caseworker, if parent/surrogate parent refuses early intervention services.
- If IFSP is developed and the foster care parent, who is not the surrogate parent, refuses EI services, the EI ongoing Service Coordinator and LDSS Foster Care Caseworker need to discuss the situation.

**EIO/Designee:**

- Reviews evaluation reports and ensures eligibility has been determined according to State EIP criteria.
- Addresses concerns raised by the initial EI Service Coordinator, evaluator, LDSS Foster Care Caseworker, parent, surrogate parent and foster care parent.
- Authorizes additional evaluations or components of the evaluation when the parent/surrogate parent or the Service Coordinator request and when necessary and appropriate.

**LDSS Foster Care Caseworker:**

- Shares information about previous health/developmental evaluations and/or other information that will influence the EI evaluation of the child with the initial EI Service Coordinator and/or evaluator.
- If circumstances warrant (e.g., child severely disabled or child has significant delays), LDSS Foster Care Caseworker may alert the LDSS attorney to request a court order, when necessary and appropriate, to arrange for provision of evaluation and services.
- Provides and shares information regarding the foster care placement that may impact on the EI service delivery and feasibility of services.

**Recommendations for consideration at the local level**

Wherever possible, the selected Early Intervention evaluator should have knowledge of relevant information concerning the child welfare system, and should have access to contact information for the LDSS Foster Care Caseworker (name, telephone number, etc.).

## **THE INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)**

### **RESPONSIBILITIES/PROCEDURES**

#### **EIO/Designee:**

- Arranges the IFSP meeting at a time and place convenient for the parent.
- Before an IFSP meeting, sends written notice to required attendees (Parent/ Surrogate Parent, EI Service Coordinator, Evaluator, and Foster Parent with parental consent) and invitations to the LDSS Foster Care Caseworker and individuals requested by the parent/surrogate parent.
- Prepares for IFSP development by reviewing reports/documentation, discussing concerns with the EI Service Coordinator, evaluator, parent, surrogate parent, foster care parent, and LDSS Foster Care Caseworker, etc.
- Convenes the initial IFSP meeting within 45 days of referral of the child to the municipality.
- Convenes the IFSP team to review the IFSP at least every six months by meeting or other means amenable to the parent/surrogate parent.
- Convenes the IFSP team to evaluate the IFSP at least annually.
- Agrees to all or part of IFSP with the parent/surrogate parent.
- Documents the child's record with IFSP decisions and identifies which part of the IFSP was agreed to or disputed.
- Notifies the LDSS Foster Care Caseworker of the results of the IFSP, if the caseworker did not participate.
- Notifies the parent or surrogate parent of due process rights for IFSP services that are in dispute.
- Notifies the LDSS Foster Care Caseworker when the parent or surrogate parent exercises due process rights for IFSP services that are in dispute.

#### **EI Service Coordinator:**

- Discusses with the parent or surrogate parent the IFSP process.
- Informs parent or surrogate parent of the required participants and optional participants, including the foster parent that can be invited to the IFSP meeting.
- Informs parent/surrogate parent of the opportunity during the evaluation to participate in the family assessment process with the evaluator. Both the parent and the foster parent may participate in the voluntary family assessment.
- Participates in the joint development of the IFSP.

#### **EI Evaluator:**

- Participates in the joint development of the IFSP.
- Clarifies evaluation findings when necessary.

#### **LDSS Foster Care Caseworker:**

- Participates in IFSP development.

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- Documents the outcome of all IFSP meetings in the UCR and relates this information to permanency planning and planning for other services.
- Considers early intervention services, when coordinating permanency planning and other services.
- If foster parent did not participate in IFSP development, notifies them of how the plan will be implemented and their obligations when early intervention services are being delivered.

## **DELIVERY OF EARLY INTERVENTION SERVICES**

### **RESPONSIBILITIES/PROCEDURES**

#### **EIO/Designee:**

- Provides oversight and ensures the delivery of authorized early intervention services.
- Monitors early intervention services and promptly corrects problems such as late service delivery, use of unqualified personnel, gaps in service delivery, delivery of unauthorized services, etc.
- Oversees circumstances when child is unavailable for services, so that the IFSP team can make a review of the appropriateness of the IFSP.
- Monitors provider billing for services.
- Participates in due process as necessary.
- Coordinates with providers and ensures that a complete record of the child's participation in the EIP is maintained.
- Shares service-related information with the LDSS Foster Care Caseworker.

#### **Ongoing EI Service Coordinator:**

- Participates in the development of IFSPs.
- Implements the IFSP and monitors the delivery of services authorized in the IFSP.
- Coordinates the provision of all early intervention services.
- Ensures that the IFSP outcomes and strategies reflect the family's priorities, concerns and resources.
- Coordinates the performance of evaluations and assessments.
- Facilitates and participates in the review and evaluation of the IFSP.
- Corrects problems regarding delivery of early intervention services that are identified through reports by the parent/surrogate parent, foster parent, provider, LDSS Foster Care Caseworker, or EIO/D, and if unable to correct problems in a timely manner, contacts the EIO/D.
- Keeps LDSS Foster Care Caseworker informed of the child's progress.
- Participates in due process as appropriate.
- Documents the early intervention service coordination record.

#### **EI Service Provider:**

- Notifies EI Service Coordinator when child is unavailable for services.
- Communicates with parent or surrogate parent regarding child's progress.
- Participates in planning for child's discharge or transition from the EIP to other services.

#### **LDSS Foster Care Caseworker:**

- Participates in the ongoing development of IFSPs.
- Notifies the EIO/D and ongoing EI Service Coordinator, if the child changes

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placement/location so that early intervention services are not disrupted.

- Notifies the EIO/D and ongoing EI Service Coordinator regarding the child's permanency goal, visitation schedule and court orders, so these can be considered when planning for or delivering early intervention services.
- Documents information about the child's participation in the EIP in the UCR.

## **MEDIATION AND IMPARTIAL HEARING DISPUTES ON ELIGIBILITY/IFSP IN THE EARLY INTERVENTION PROGRAM**

### **RESPONSIBILITIES/PROCEDURES**

#### **EIO/Designee:**

- Provides written notice to parent or surrogate parent of the right to due process when:
  - child is found ineligible;
  - parent/surrogate parent and EIO/D disagree about the services that are included in the IFSP (type, quantity, setting, etc.);
  - parent/surrogate parent is dissatisfied with service provision, and the problem cannot readily be resolved.
- Receives request for mediation from parent/surrogate parent and forwards to community dispute resolution center.
- Receives notice of impartial hearing from the Department of Health, Division of Legal Affairs.
- Participates in mediation and/or impartial hearing.
- Amends the record, including the IFSP, if applicable, according to mediation and impartial hearing decisions.
- Advises LDSS Foster Care Caseworker of decision and changes to IFSP resulting from mediation/impartial hearing.
- Implements terms of mediation/impartial hearing decisions.

#### **EI Service Coordinator:**

- Discusses due process rights with parent/surrogate parent when concerns cannot be readily resolved.
- Clarifies/answers questions from parent/surrogate parent regarding due process.
- Participates in mediation, if invited, and impartial hearing, if summoned.
- Amends the service coordination record, if applicable, according to mediation and impartial hearing decisions.
- Keeps LDSS Foster Care Caseworker apprised of due process decisions either by phone or in writing.
- Monitors services according to terms of mediation/impartial hearing decisions.

#### **LDSS Foster Care Caseworker:**

- Participates in mediation when invited and impartial hearing when summoned.
- Documents the UCR of any changes in the child's early intervention services as a result of due process decisions.

## **TRANSITION/DISCHARGE FROM THE EARLY INTERVENTION PROGRAM**

### **RESPONSIBILITIES/PROCEDURES**

#### **For all children transitioning from the EIP**

##### **EI Ongoing Service Coordinator:**

- Explains transition process to parent/surrogate parent and LDSS Foster Care Caseworker.
- Sets up a meeting to discuss the transition plan to preschool or other early childhood services.
- Participates in the IFSP and other meetings to discuss and plan for transition.
- If applicable, includes in the IFSP steps to be taken supporting the potential transition. The plan for transition should include procedures to prepare the child and family for changes in service delivery or to other appropriate early childhood and supportive services.
- Reviews information concerning the transition process with the parent/surrogate parent and LDSS Foster Care Caseworker.
- Links the child and parent/surrogate parent to other community services the child is potentially eligible for.
- Obtains parental consent for the transfer of appropriate evaluations, assessment, IFSP, and other pertinent records.

##### **LDSS Foster Care Caseworker:**

- Coordinates with the EI Ongoing Service Coordinator and the parent/surrogate parent on the referral process.
- Notifies the EIO/D and EI Ongoing Service Coordinator that the referral has been made.
- Attends the IFSP meeting and transition conference meeting.
- Documents the foster care record with the child's plan for transition from the EIP and discharge activities.
- In coordination with EI Ongoing Service Coordinator, facilitates the child's transition from the EIP as necessary.

#### **For children potentially eligible for the Preschool Special Education Program**

(See **Appendix H-** Criteria for Eligibility for Preschool Special Education Programs and/or Services.)

##### **EIO/Designee:**

- Discusses with the parent/surrogate parent the transition process.
- Notifies the LDSS Foster Care Caseworker and parent/surrogate of procedures to determine whether the child is eligible for services under Section 4410 of the NYS Education Law, which serves children ages 3-5 years with disabilities and developmental delay.

- Coordinates with the LDSS Caseworker to work with the parent/surrogate parent to develop a transition plan.
- For children referred to the CPSE, obtains parent/surrogate consent to transfer evaluations, assessments, IFSPs and other pertinent early intervention records to the CPSE.
- Arranges for a conference, with parental consent, with the service coordinator, the parent/surrogate parent, and the chairperson of the committee on preschool special education or designee to review the child's program options and to establish a transition plan, if appropriate.
- Invites the local social services commissioner/designee to participate in the conference.

**Board Of Education/CPSE:**

- CPSE requests written consent from the parent to conduct the individual evaluation.
- The Board of Education (BOE) must adhere to the Regulations of the Commissioner of Education Part 200, in the appointment of a surrogate parent to act in place of parents or guardians when a student's parents or guardians are not known, or when after reasonable efforts, the board of education can not discover the whereabouts of a parent or, the student is a ward of the State. The BOE appoints from the list of surrogate parents kept by the Board.
- With parental consent, the chairperson of the CPSE or designee participates in a conference with the parent/surrogate parent, service coordinator, to review program options for the child. (Note: the conference may also be an IFSP meeting and may be combined with the initial CPSE meeting).

**Recommendations for consideration at the local level**

Develop an interagency agreement between the municipal EIP and LDSS that will address the referral process of children transitioning out of the EIP to CPSE.

## STATE CONTACT INFORMATION

For more information about the New York State Early Intervention Program and Public Health Law requirements, contact:

New York State DOH Early Intervention Program  
Room 287 Corning Tower Building  
Empire State Plaza  
Albany, New York 12237-0618  
Phone: 518-473-7016  
Fax: 518-486-1090  
E-mail: [eip@health.state.ny.us](mailto:eip@health.state.ny.us)  
[www.health.state.ny.us/nysdoh/eip/index.htm](http://www.health.state.ny.us/nysdoh/eip/index.htm)

For more information about the foster care system, contact:

New York Office of Children and Family Services  
[www.dfa.state.ny.us](http://www.dfa.state.ny.us)

## APPENDIX A - Definitions

**Basic Medical Evaluation** - LDSS is required to provide a comprehensive health assessment within 30 days of the child entering foster care that includes hearing and vision screening and an assessment to determine if the child requires services to address developmental delays.

**Case Manager** - individual responsible for "legal sign off" on all plans, all placements and all decisions regarding the child in the Foster Care System.

**Case Planner – 18 NYCRR Part 428** - assigned from the agency under contract that is responsible for the foster care placement. The case manager develops permanency plans after consultation and collaboration with the foster care agency caseworker and the birth parent. Although the contract agency case manager is the day-to-day contact and planner for the child, the contract agency is required to have the case manager sign off on all decisions/changes regarding the child's care in the Foster Care System.

**Child Protective Proceedings** - Proceedings brought by the local department of social services on behalf of children alleged to be abused and/or neglected. The standards and procedures described in Article 10 of the Family Court Act. One possible outcome of such proceedings is the child's placement into foster care/custody of the local commissioner of social services.

### Children at Risk

- **Defined by Early Intervention** as children at risk for developmental delay. The following risk criteria may be considered by the primary referral source in the decision to make a referral to the Early Intervention Program, for example:
  - No prenatal care;
  - Parental developmental disability or diagnosed serious and persistent mental illness;
  - Parental substance abuse, including alcohol or illicit drug abuse;
  - No well child care by 6 months of age or significant delay in immunizations; and/or,
  - Other risk criteria as identified by the primary referral source.
- **Defined by Social Services** as child who experiences parental neglect or abuse, or can not provide the child with a safe, permanent living arrangement.

**Due Process** - procedures designed to protect a person's rights. This includes requirements for confidentiality, consent, and processes to resolve disagreements and file complaints.

**Early Intervention Official /Designee (EIO/D)** – an appropriate municipal official designated by the chief executive officer of a municipality and an appropriate designee of such official. This is the responsible person for the Early Intervention Program in that municipality.

**Family Assessment** – An optional component of the evaluation process that is family-directed and designed to determine the resources, priorities, and concerns of the family related to enhancement of the child's development. Family assessment is voluntary on the part of the family.

**Individualized Family Service Plan (IFSP)** - a written plan for the child's and family's services in the Early Intervention Program that the family develops with a team of qualified personnel and the EIO/D.

**Interim Individualized Family Service Plan** - when the child and/or family are in apparent immediate need of early intervention services, a temporary IFSP can be developed to allow the child and family to receive early intervention services after the child has been referred to the program and before an evaluation is completed.

**LDSS District** - the local departments of social services - includes the NYC Administration for Children's Services and the 57 county departments of social services and the St. Regis Mohawk Tribe.

**Mediation** - a voluntary, non-adversarial process by which the parent of a child and the early intervention official or designee are assisted in the resolution of a dispute. In mediation, the parent and the Early Intervention Official try to reach an agreement with which both are satisfied.

**Municipality** - a county outside of the City of New York or the City of New York in the case of a county contained within the City of New York.

**Parent** - a parent by birth, adoption, or person in parental relation to the child and surrogate parent. Person in parental relation means:

- the child's legal guardian;
- the child's standby guardian;
- the child's custodian (a person who has assumed the charge and care of the child);
- person acting in the place of a parent (grandparent or stepparent with whom the child lives and who is legally responsible for the child's welfare).

**Parental Rights Terminated** - Unless parents have voluntarily surrendered guardianship and custody of the child or the Family Court or Surrogate's Court has terminated the parent's rights (i.e. involuntarily terminated the parent's guardianship and custody of the child), the parent still has rights and must be actively involved in services planning and decision-making.

**Service Coordinator** –

**Initial Service Coordinator** - assigned by the EIO/D, helps to work with the family with all the steps of the first Individualized Family Service Plan.

**Ongoing Service Coordinator** - selected by the parent; is responsible for coordinating the services provided by various personnel included in the IFSP; working with the family to enhance the child's development; monitoring the child's progress to identify changes needed in the plan; and, preparing and coordinating the six-month and annual review of the family service plan.

**Surrogate Parent** – a person who is appointed by the EIO/D to act in place of the parent when the parent(s) are not available to participate in making decisions about the child’s involvement in the Early Intervention Program. The surrogate parent has the same rights and responsibilities as accorded to the parent by the Early Intervention Program and will represent the child in all matters related to the Early Intervention Program.

**Ward of the State** – a term used in the Early Intervention Program referring to a child whose custody and guardianship have been transferred to the local social services official pursuant to a voluntary surrender by the child's parent or by a family court or surrogate court in conjunction with the termination of the parental rights of the child's parent.

**APPENDIX B - Children's Eligibility Status Based on Diagnosed Conditions with High Probability**

**The following information is from  
NYS DOH EI Memorandum Document 99-2- Appendix A**

### **APPENDIX C - Required Early Intervention Primary Referral Sources**

EIP Primary Referral Sources under Public Health Law (PHL) are to refer a child less than three years of age who they suspect of having or being at risk of a developmental delay, to the local EI Official within two working days of identification. Parental consent is not required; however, parents may object to a referral. If the parent objects to the referral then the primary referral source must document the objection and make reasonable efforts to follow up with the parent within two months.

#### EIP Primary Referral Sources

Hospital

Child Health Care Providers

Local Health Facilities

Article 28 Clinics

Article 16 Clinics

Article 31 Clinics

Day Care programs

Early Childhood Direction Centers

School Districts

Social Service Districts

EI Service Providers

All qualified personnel under the EI law

## **APPENDIX D - Mandated Reporters of Child Abuse and Maltreatment**

Many, though not all, of the professionals who are required to report incidents of suspected child abuse and maltreatment (mandated reporters) are also required to make referrals for infants and toddlers suspected of having, or being at risk of, a developmental delay (primary referral sources). The persons indicated below are mandated to report when they have reasonable cause to suspect that a child has been abused or maltreated when the child, guardian, parent or other legal responsible party is before them in their official or professional capacity. Neither parental consent nor notification is necessary, and parental objection does not remove the obligation.

Mandated reporters of child abuse and maltreatment are required to report suspected incidents of abuse and maltreatment (of children up to age 18) to the NYS Child Abuse Hotline (1-800-635-1522). Two districts, Onondaga (315) 422-9701 and Monroe (585) 461-5690, maintain their own child abuse and maltreatment hotline numbers.

### **Mandated Reporters of Child Abuse & Maltreatment**

Physicians/Registered Physician Assistants	Providers of Family or Group Family Day Care
Surgeons	School Officials
Medical Examiners, Coroners	Social Services Workers
Dentists/Hygienists	Employees or Volunteers in a Residential Care Facility or Other Child Care or Foster Care Workers
Optometrists	Mental Health Professionals
Chiropractors	Substance Abuse Counselors
Osteopath	Alcoholism Counselors
Residents	Peace Officers
Psychologists	Police Officers
Interns	District Attorneys/Assistant District Attorneys
Podiatrists	Investigators employed in the office of a district attorney
Emergency Medical Technicians	Other law enforcement officials
Hospital personnel engaged in the admission, examination, care of treatment of persons	<b>Effective September 1, 2004</b>
Registered Nurses	Social Workers
Christian Science Practitioners	
Day Care Center Workers	

## **APPENDIX E - Definition of Medical Neglect**

A *parent* or other person legally responsible for the child must supply adequate medical, dental, optometrical or surgical care if financially able to do so or offered financial or other reasonable means to do so.

This includes:

- Seeking adequate treatment for conditions, which impair or threaten to impair the child's mental, emotional or physical condition;
- Following prescribed treatment for remedial care including psychiatric and psychological services;
- Obtaining preventive care such as postnatal check-ups, and immunizations for polio, mumps, measles, diphtheria and rubella.

The parent's failure to seek or follow adequate treatment or desire to select an unconventional form of treatment must be considered in light of:

- The seriousness of the child's conditions and risk of further harm to the child;
- The parent's awareness of the child's condition and risk of further harm to the child;
- Whether the parent has sought accredited medical opinion;
- The consensus of responsible medical authority regarding treatment;
- Whether the parent's failure to seek adequate treatment or select an unconventional form of treatment impairs the child physically or emotionally;
- Whether the parent fails to seek adequate treatment despite financial or other reasonable means to do so.

Article 10 of the Family Court Act authorizes intervention not only in life and death emergencies, but also in situations where a child is denied adequate medical, dental, optometrical, or surgical care due to the parent's or person legally responsible's failure to provide "...an acceptable course of medical treatment for their child in light of all the surrounding circumstances." The Court's inquiry should be whether the parents, once having sought accredited medical assistance, and having been made aware of the seriousness of their child's affliction, and the possibility of cure if a certain mode of treatment is undertaken have provided for their child a treatment which is recommended by their physician, and which has not been totally rejected by all responsible medical authority. In the Matter of Hofbauer, 47 N.Y. 2d 648, 393 N.E. 2d 1009, 419 N.Y.S. 2d 936 (1979).

The same test applies in cases in which a parent objects to medical treatment based on religious belief. The focus must be whether the parents have provided an acceptable course of medical treatment for their child in light of all the surrounding circumstances. A child who has been harmed or who is in imminent danger of harm, as a result of a parent's failure to supply adequate medical, dental, optometrical or surgical care, although financially able to do so or offered reasonable means to do so is a neglected child. In the Matter of Gregory S. et al, 85 Misc. 2d 845, 380 N.Y.S. 2d 620, (Fam. Ct., Kings Co. 1976)

## IMMEDIATE CONSIDERATIONS

- In the opinion of accredited medical professionals, what is the nature and extent of the child's condition?
- Did the parent seek accredited medical assistance for the child?
- What do responsible medical authorities prescribe as the recommended form of treatment? Identify authorities by name and address.
- What is the parent's explanation for this course of action? Have inadequate finances blocked parental ability to obtain treatment? Good note taking is essential. Use direct quotes.
- Has the child's condition been impaired or at imminent risk of impairment by parental actions or failures to act? Have the parents exercised a minimum degree of care of the child?

**APPENDIX F - Definition of Abuse and Maltreatment**

NEW YORK STATE CONSOLIDATED LAWS  
Social Services  
TITLE 6 CHILD PROTECTIVE SERVICES

Article 10 Family Court Act (FCA) 1012(e)

"Abused child" means a child less than eighteen years of age whose parent or other person legally responsible for his care

- (i) inflicts or allows to be inflicted upon such child physical injury by other than accidental means which causes or creates a substantial risk of death, or serious or protracted disfigurement, or protracted impairment of physical or emotional health or protracted loss or impairment of the function of any bodily organ, or
- (ii) creates or allows to be created a substantial risk of physical injury to such child by other than accidental means which would be likely to cause death or serious or protracted disfigurement, or protracted impairment of physical or emotional health or protracted loss or impairment of the function of any bodily organ, or
- (iii) commits, or allows to be committed an offense against such child defined in article one hundred thirty of the penal law; allows, permits or encourages such child to engage in any act described in sections 230.25, 230.30 and 230.32 of the penal law; commits any of the acts described in section 255.25 of the penal law; or allows such child to engage in acts or conduct described in article two hundred sixty-three of the penal law provided, however, that
  - (a) the corroboration requirements contained in the penal law and
  - (b) the age requirement for the application of article two hundred sixty-three of such law shall not apply to proceedings under this article.

Article 10 Act (FCA) 1012(f)

"Neglected child" means a child less than eighteen years of age

- (i) whose physical, mental or emotional condition has been impaired or is in imminent danger of becoming impaired as a result of the failure of his parent or other person legally responsible for his care to exercise a minimum degree of care
  - (a) in supplying the child with adequate food, clothing, shelter or education in accordance with the provisions of part one of article sixty-five of the education law, or medical, dental, optometrical or surgical care, though financially able to do so or offered financial or other reasonable means to do so; or
  - (b) in providing the child with proper supervision or guardianship, by unreasonably inflicting or allowing to be inflicted harm, or a substantial risk thereof, including the infliction of excessive corporal punishment; or by misusing a drug or drugs; or by misusing alcoholic beverages to the extent that he loses self-

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control of his actions; or by any other acts of a similarly serious nature requiring the aid of the court; provided, however, that where the respondent is voluntarily and regularly participating in a rehabilitative program, evidence that the respondent has repeatedly misused a drug or drugs or alcoholic beverages to the extent that he loses self-control of his actions shall not establish that the child is a neglected child in the absence of evidence establishing that the child's physical, mental or emotional condition has been impaired or is in imminent danger of becoming impaired as set forth in

- (i) paragraph of this subdivision; or
- (ii) who has been abandoned, in accordance with the definition and other criteria set forth in subdivision five of section three hundred eighty-four-b of the social services law, by his parents or other person legally responsible for his care.

## **APPENDIX G - Referral of Children at Risk**

### Sec. 69-4.3(f) Referrals

Referrals of children at risk of having a disability shall be made based on the following medical/biological risk factors:

- (1) Medical/biological neonatal risk criteria, including:
  - birth weight less than 1501 grams
  - gestational age less than 33 weeks
  - central nervous system insult or abnormality (including neonatal seizures, intracranial hemorrhage, need for ventilator support for more than 48 hours, birth trauma)
  - congenital malformations
  - asphyxia (Apgar score of three or less at five minutes)
  - abnormalities in muscle tone, such as hyper- or hypotonicity
  - hyperbilirubinemia (> 20mg/dl)
  - hypoglycemia (serum glucose under 20 mg/dl)
  - growth deficiency/nutritional problems (*e.g.*, small for gestational age; significant feeding problem)
  - presence of Inborn Metabolic Disorder (IMD)
  - perinatally- or congenitally-transmitted infection (*e.g.*, HIV, hepatitis B, syphilis)
  - 10 or more days hospitalization in a Neonatal Intensive Care Unit (NICU)
  - maternal prenatal alcohol abuse
  - maternal prenatal abuse of illicit substances/prenatal exposure to move to new one therapeutic drugs with known potential developmental implications (*e.g.*, psychotropic medications, anticonvulsant, antineoplastic)
  - maternal PKU
  - suspected hearing impairment (*e.g.*, familial history of hearing impairment or loss; suspicion based on gross screening measures)
  - suspected vision impairment (suspicion based on gross screening measures)
  
- (2) Medical/biological post-neonatal and early childhood risk criteria, including:
  - parental or caregiver concern about developmental status
  - serious illness or traumatic injury with implications for central nervous system development and requiring hospitalization in a pediatric intensive care unit for ten or more days
  - elevated venous blood lead levels (above 19 mcg/dl)
  - growth deficiency/nutritional problems (*e.g.*, significant organic or inorganic failure-to-thrive, significant iron-deficiency anemia)

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chronicity of serous otitis media (continuous for a minimum of three months)  
HIV infection

The following risk criteria may be considered by the primary referral source in the decision to make a referral:

- (1) no prenatal care
- (2) parental developmental disability or diagnosed serious and persistent mental illness
- (3) parental substance abuse, including alcohol or illicit drug abuse
- (4) no well child care by 6 months of age or significant delay in immunizations; and/or
- (5) other risk criteria as identified by the primary referral source

## **APPENDIX H - Criteria for Eligibility for Preschool Special Education Programs and/or Services**

Part 200 of the Regulations of the Commissioner states, "Eligibility as a preschool student with a disability shall be based on the results of an individual evaluation which is provided in the student's native language, not dependent on a single procedure, and administered by a multidisciplinary team in accordance with all other requirements as described in section 200.4(b) and 200.16(c) of the regulations.

1. Commencing July 1, 1993, to be identified as having a disability, a preschool student shall either:

- (i) exhibit a significant delay or disability in one or more functional areas related to **cognitive, language and communicative, adaptive, socio-emotional or motor development** which adversely affects the student's ability to learn. Such delay or disability shall be documented by the results of the individual evaluation which includes but is not limited to information in all functional areas obtained from a structured observation of a student's performance and behavior, a parental interview and other individually administered assessment procedures, and, when reviewed in combination and compared to accepted milestones for child development, indicate:

- a. a 12-month delay in one or more functional area(s); or
- b. a 33 percent delay in one functional area or a 25 percent delay in each of two functional areas; or
- c. if appropriate standardized instruments are individually administered in the evaluation process, a score of 2.0 standard deviations below the mean in one functional area, or a score of 1.5 standard deviations below the mean in each of two functional areas; \* or

- (ii) meet the criteria set forth in paragraphs (1), (2), (3), (5), (9), (10), (12), or (13) of subdivision (zz) of this section.

\*Calculated on the basis of months

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**APPENDIX I - Office of Children and Family Services Commissioner Letter**

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New York State  
Office of  
Children & Family  
Services

May 27, 1999

Dear Commissioner:

George E. Pataki  
Governor

John A. Johnson  
Commissioner

The Office is sending this letter to clarify the authority of social services districts in regard to foster children who are participating in the Early Intervention Program for Infants and Toddlers with Disabilities (EI Program) administered by the New York State Department of Health (DOH). The Office was asked to issue this letter because questions were recently raised by social services districts and EI programs regarding what role social services officials could have in such cases. In particular, the issue of when a surrogate parent is appointed was identified.

Capital View Office Park  
52 Washington Street  
Rensselaer, NY 12144-2796

The EI program is a statewide mechanism which identifies infants and toddlers with disabling conditions and evaluates their needs for a range of early intervention services. The EI program also develops individualized family service plans to address such needs. The statutory authority for the EI program is set forth in Article 25 of the Public Health Law and implementing regulations are set forth in 18 NYCRR Part 69.

Foster children who otherwise satisfy the eligibility requirements for the EI program are entitled to benefit from this program. When a foster child is in receipt of early intervention services, the early intervention official must make every effort to protect the right of parents to make decisions about a child's receipt of early intervention services. Also, the early intervention official must facilitate the involvement of the parent of a foster child in early intervention services.

The situation may arise where the early intervention official determines that a person needs to be appointed to serve in the position of a surrogate parent for EI program purposes. A qualified surrogate parent shall be appointed by the EI official when the child is a ward of the State or when the child is not a ward of the State. A ward of the State is defined to mean a child whose custody and guardianship have been transferred to a social services official pursuant to a voluntary surrender or an involuntary termination of parental rights.

A surrogate parent shall also be appointed when: i) a child is not a ward of the State; ii) his or her parents are unavailable after reasonable efforts to facilitate their participation and iii) the child has no person or parent relation. A person in parent relation means:

- (1) the child's legal guardian;



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- (2) the child's standby guardian after their authority becomes effective pursuant to section 1726 of the Surrogate's Court Procedure Act;
- (3) the child's custodian; a person shall be regarded as the custodian of a child if he or she has assumed the charge and care of the child because the parents or legally appointed guardian of the minor have died, are imprisoned, are mentally ill, or have been committed to an institution, or because they have abandoned or deserted such child or are living outside the state or their whereabouts are unknown; or
- (4) persons acting in the place of a parent, such as a grandparent or stepparent with whom the child lives, as well as persons who are legally responsible for the child's welfare;
- (5) except, this term does not apply to a child who is a ward of the State, and does not include a foster parent.

A surrogate parent may be appointed voluntarily by the child's parent. In accordance with 18 NYCRR 169 - 4.16(e), the early intervention official must select a surrogate parent who is qualified and willing to serve and who:

- (1) has no interest that conflicts with the interests of the child;
- (2) has knowledge and skills that ensure adequate representation of the child;
- (3) if available and appropriate, is a relative who has an ongoing relationship with the child or a foster parent with whom the child resides;
- (4) is not an employee of any agency involved in the provision of early intervention or other services to the child, provided however that a person who otherwise qualifies to be a surrogate parent is not considered an employee solely because he or she is paid by a public agency to serve as a surrogate parent; and
- (5) has been selected, for any child who is a ward of the State or for any child whose parent is unavailable and who is in the care and custody of the local social services commissioner, in consultation with the local commissioner of social services or designee.

In accordance with both federal and State standards, a surrogate parent may not be the commissioner of the social services district because of the role of the social services district in the provision of services to the child. However, the social services district does play an integral role in the EI program. The duties and responsibilities include:

- a) The early intervention official must establish an agreement with the social services district to identify eligible or potentially eligible foster children. The early intervention official must consult with the social services district to determine the availability of the parent and, if the parent is not available, to identify a suitable surrogate parent.

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The regulations promulgated by DOH also reference procedural safeguards. The local social services district, the local commissioner of social services or his or her designee is authorized to have access to records collected, maintained or used for EI program purposes. The local commissioner of social services or his or her designee is afforded notice and a right to be heard at any mediation or hearing relating to early intervention services provided to a foster child. The local commissioner of social services is not afforded standing rights at such proceedings.

The social services district retains case management responsibility over its foster child. The social services district continues to be responsible for casework, programmatic and legal activities in regard to the foster child. As stated above, the local commissioner can not serve as the surrogate parent, although a foster parent may. The local commissioner does have rights relating to access to records relating to the foster child and to be heard at administrative proceedings involving the foster child.

Clearly, the social services district and the EI program have mutual interests. The experience of this Office and DOH has been that both parties can work cooperatively to serve children and families.

Please contact your OCFS Regional Office if you wish to discuss these issues or if you have any questions.

Sincerely,



William F. Baccaglini, Director  
Strategic Planning and Policy Development

cc: Donna Noyes, NYSDOH  
OCFS Regional Office Directors

## References

*"Project Interface, Policy & Procedure Manual," developed and produced by InterAgency Council of Mental Retardation & Developmental Disabilities Agencies, Inc.*

*May 27, 1999 letter from William F. Baccaglioni, Director, Strategic Planning and Policy Development, NYS Office of Children & Family Services to local department of social service commissioners, regarding the authority of social services districts in regard to foster children participating in the EIP.*

*"Tool Kit for Ensuring the Healthy Development of Children in Foster Care," developed by the NYS Permanent Judicial Commission on Justice for Children.*

*"Developmental Issues for Young Children in Foster Care," policy statement developed by the American Academy of Pediatrics, published in Pediatrics, Nov. 2000, Vol. 106, No.5, pp1145-1150*

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## **I. Syndromes/Conditions**

### **Conditions**

#### **Cleft Palate—749.00**

##### Description:

Cleft palate is a congenital fissure in the median line of the palate (bony roof of the mouth) which may extend through the uvula, soft palate, and hard palate; cleft lip may or may not be involved. Clefts involving the palate and/or lip are classified several ways; classification systems differ in terms of anatomical references (e.g. the American Cleft Palate Association differentiates between clefts of the prepalate (lip and alveolar process) while Davis and Ritchie consider the position of the cleft relative to the alveolar process. Regardless of the specific classification system used, clefts may be unilateral, bilateral, complete or total and incomplete, partial or subtotal. One other type is called a submucous cleft. These are further defined below.

- Complete or total: cleft palate in which the cleft extends from the lip through the alveolar process, hard palate and soft palate.
- Incomplete, partial or subtotal: cleft palate in which the cleft can be limited to the lip, alveolar process, hard palate, or soft palate, or a combination of these structures.
- Bilateral: failure of the palate on the right and left sides to fuse to the nasal partition or septum.
- Unilateral: fusion of the palate to the vertical nasal septum only on one side.
- Submucous: condition in which the surface tissues of the hard or soft palate unite but the underlying bone or muscle tissues do not; also called occult cleft palate.

##### Effects/Prognosis:

Cleft palate is associated with feeding and swallowing problems, failure to thrive (poor growth), aspiration, recurrent ear infections and hypernasal, dysarticulate speech. Specific speech/language characteristics also include nasal emission of air during production of fricative sounds and delayed development of language skills. Undesirable facial distortions or mannerisms may also accompany speech.

#### **Extreme Prematurity**

**Less than 500 grams—765.01**

**500-749 grams—765.02**

**750-999 grams—765.03**

##### Description:

Infants weighing less than 1500 grams are referred to as very-low-birth-weight (VLBW) babies and comprise 1.15 % of all births in the U.S. For infants born with birth-weights below 2500 grams, the mortality rate rapidly increases with decreasing weight, and most of the infants weighing 1000 grams or less do not survive. The average length of hospital stay for infants weighing 1000 grams or less is 89 days, with shorter lengths of stay for those who do not survive.

#### Effects/Prognosis:

Outcomes for this population are variable. Very low birth weight babies are at increased risk for neurodevelopmental complications. Ten to fifteen percent of surviving VLBW infants are affected by major deficits including spastic motor dysfunction (cerebral palsy) and associated mental retardation. These deficits appear to result largely from two defined lesions: intraventricular hemorrhage (IVH) and periventricular leucomalacia (PVL). Grade III and IV IVH are associated with major deficits in 50 to 90% of survivors. Outcomes for PVL are correlated with outcomes for Grades III and IV IVH. Other complications in VLBW babies may include breathing problems (hyaline-membrane disease or respiratory distress syndrome), feeding difficulties, seizure disorders, hydrocephalus, retinopathy of prematurity (also called retrolental fibroplasia) and increased risk for serious or protracted illness. Other associated problems of prematurity include heart abnormalities, renal problems and vision and hearing problems. Re-hospitalization during the first year of life is not uncommon; 40% of VLBW infants have almost two hospitalizations with an average of 16 days in the hospital in the first year of life. The average number of physician visits is also higher than for infants of normal birth-weight, ranging from 14-16 visits (compared with 10 visits for normal birth-weight babies). The presence of a congenital anomaly or developmental delay was a determining factor in physician use. Longer term problems for these infants may include behavior problems at preschool age and decreased performance on standardized IQ tests.

### **Syndromes/Chromosomal Abnormalities**

#### **Angleman's Syndrome (syndromes affecting multiple systems)--759.89**

##### Description:

Angleman's Syndrome is a disorder characterized by severe mental retardation with marked delay in attaining motor milestones, episodes of inappropriate laughter and limited or absent speech. Other signs include ataxia and jerky arm movements, said to resemble a "puppet gait." Seizure activity is most severe at about age 4 years and may stop by age ten years. Decreased need for sleep between ages 2 and 6 years has also been reported.

##### Effects/Prognosis:

Severe difficulties with speech; most individuals communicate using alternate means (e.g. sign language). Receptively, simple commands may be understood. Most individuals become toilet trained by day and some by night. All require a supported living arrangement.

#### **CHARGE Association (multiple anomalies)--759.7**

##### Description:

CHARGE Association is an association of multiple congenital malformations including: absence of part of the eye or retina (coloboma), heart disease, nasal blockage (choanal atresia), retarded growth and development with mental retardation ranging from mild to profound, genital anomalies, ear anomalies and sensorineural hearing loss. Visual and auditory problems may further compromise cognitive function. Other findings may include, but are not limited to: a small jaw (micrognathia), cleft lip, cleft palate, multiple

cranial nerve abnormalities, facial palsy, feeding difficulties resulting from poor suck and velopharyngeal incompetence, kidney (renal) anomalies and growth hormone deficiency.

Effects/Prognosis:

Effects depend on the severity of the defects. In some cases, death occurs shortly after birth due to respiratory insufficiency or heart disease. In less severely involved individuals, most show some degree of mental deficiency and/or CNS defects, along with visual and auditory deficits. Feeding difficulties, facial palsy and sensorineural hearing loss are related to cranial nerve abnormalities.

**Down syndrome (trisomy 21 or 22,G)—758.0**

Description:

Down Syndrome is a chromosomal disorder including the following clinical features: hypotonia (decreased muscle tone), short stature, flat facial profile, epicanthal folds, upslanting eye slits, small ears, speckling of the iris, cardiac defects, duodenal atresia, atlantoaxial instability (enlargement of distance between first two neck vertebrae that leaves the individual susceptible to spinal cord compression and neurological involvement), thyroid disorders, hearing loss (may be conductive, mixed or sensorineural) and mental retardation. Other attributes include poor coordination and relatively slow physical growth in the first 8 years. Sleep-related upper airway obstruction has been reported in about one third of cases.

Effects/Prognosis:

Multi-system disorder with varying degrees of severity. The I.Q. range is reported to be between 25 and 50 with occasional individuals above 50. Varying degrees of hearing loss and speech impairment are also associated. Social performance is usually beyond expectations for mental age.

**Edwards' Syndrome (Trisomy 18, E3)—758.2**

Description:

Edwards' Syndrome is a chromosomal syndrome and the second most common multiple malformation syndrome, with an incidence of 1/3000 births. Clinical findings include clenched hands with overlapping fingers, rocker-bottom feet (rigid flat feet), short sternum, heart disease, severe mental retardation and failure to thrive (poor growth). Poor sucking capability contributes to failure to thrive and may necessitate nasogastric feeding. Other characteristics include hypertonicity (after the neonatal period) and diminished response to sound.

Effects/Prognosis:

Babies with this syndrome are described as feeble and have limited capacity for survival. Resuscitation is often performed at birth and episodes of apnea may occur in the neonatal period. Fifty percent die within the first week and many of those remaining die within the first twelve months. Five to ten percent survive the first year. These individuals are typically unable to walk independently and usually have a very limited expressive vocabulary (a few single words). Some older children with Trisomy 18 reportedly smile, laugh and interact with their families. All are reported to achieve some psychomotor maturation and to continue to learn.

### **Fetal Alcohol Syndrome—760.71**

#### Description:

Fetal Alcohol Syndrome (FAS) is a syndrome resulting from effects of maternal alcohol ingestion. Malformations are caused in the developing fetus. Clinical findings in FAS include pre-and postnatal growth retardation, mild to moderate microcephaly, cognitive deficits (usually mild to moderate in degree) and characteristic facial features including short eye slits (palpebral fissures) and a smooth indentation in the upper lip below the nose (philtrum). A heart murmur may be present, frequently disappearing by 1 year of age. Associated difficulties may include myopia, strabismus (cross eye/squint), hearing loss, dental malocclusion, eustachian tube dysfunction, articulation problems, language disorders, specific learning disabilities and attention deficit/hyperactivity disorder. Incidence figures show 1/300 babies show some effect of maternal ingestion of alcohol and more than 1/1000 show the full-blown syndrome.

#### Effects/Prognosis:

Individuals with FAS may appear similar to those with “failure to thrive.” They tend to be irritable as infants and hyperactive as young children. A diagnosis of mild mental retardation is frequently reported. In general, the severity of the maternal alcoholism and the extent and severity of the pattern of malformation are predictive of the ultimate prognosis. A follow up study of a group of adolescents and adults with FAS (average age 18 years) revealed academic functioning at a fourth grade level with difficulty in mathematics noted. Other common behavioral characteristics in this group included poor judgement, distractibility and difficulty recognizing social cues.

### **Fragile X Syndrome—759.83**

#### Description:

Fragile X Syndrome is also known as Martin-Bell syndrome, Marker X syndrome and Escalante syndrome. This is a genetic syndrome characterized by mental retardation ranging from mild to profound in males. Attention problems related to hyperactivity and autism are commonly seen. Other features include macrocephaly (abnormally large head) and macrosomia (large body size) in early childhood, thickening of the nasal bridge extending down to the tip of the nose, large ears, pale blue eyes, epicanthal folds (crescent-shaped folds of skin extending down from the side of the nose to the lower eye lid and partially covering the inner corner of the eye opening) and dental crowding. Hand flapping or biting and poor eye contact are also characteristic. A speech pattern called “cluttering” (rapid speech with some syllables omitted; may be difficult to understand) is also typical in higher functioning individuals. Occasional associated abnormalities may include submucous cleft palate and heart disease. In females, involvement tends to be mild; shyness, anxiety and panic attacks are reportedly seen.

#### Effects/Prognosis:

Effects are dependent on the degree of cognitive involvement and are more pronounced in males. Females typically show milder effects but do have educational difficulties.

### **Patau’s Syndrome (Trisomy 13, D1)—758.1**

#### Description:

Patau’s Syndrome is a chromosomal disorder with multi-system involvement with an estimated incidence of 1/8000 births. Clinical findings include microcephaly

(abnormally small head), incomplete development of the forebrain, severe mental retardation, clefting (lip and palate), hyperconvex nails and extra fingers or toes (polydactyly). Other characteristic abnormalities include: apneic spells in early infancy, deafness, visual deficits and heart disease in more than 50% of cases. Fewer than one child in five survives the first year of life. Advanced maternal age is a contributing factor in the occurrence of this syndrome.

Effects/Prognosis:

The average survival for children with this disorder is 2.5 days, with only 5% surviving the first 6 months. Survivors reportedly have severe mental defects and fail to thrive. Seizures are also typical.

**Prader-Willi Syndrome—759.81**

Description:

Prader-Willi Syndrome is also known as HHHO syndrome (Hypotonia-Hypogonadism-Hypomentia-Obesity syndrome). This is a genetic syndrome characterized by severe obesity, mental retardation (primarily in the mild to moderate range), poor muscle tone in infancy, short stature, small hands and feet, incomplete sexual development and behavior problems. Feeding problems are associated with this disorder in infancy and tube feeding is sometimes necessary. The hypotonia may cause respiratory problems as well. Failure to thrive may occur in early infancy; followed by a marked change with the development of an insatiable appetite. Onset of obesity may occur between age 6 months and 6 years, and is related to increased intake with reduced activity. At the same time, the hypotonia generally improves.

Three phases are identified: 1. infancy with decreased muscle tone (hypotonia) and failure to thrive; 2. childhood with features including almond-shaped eyes, small eye slit length, ravenous appetite (hyperphagia), cognitive deficits (ranging from mental retardation to learning disabilities and language impairments) and 3. young adulthood with increased severity of the childhood symptoms along with severe emotional and behavioral symptoms.

Effects/Prognosis:

Typical effects include mental retardation, most often in the mild to moderate range. Dietary management is key to prolonging life expectancy and reducing the chances of complications related to morbid obesity (e.g. cardiac complications). Speech problems (articulation) and hypernasal speech are noted. The individual may also persevere on favorite topics.

**II. Neuromuscular/Musculoskeletal Disorders**

**Congenital Muscular Dystrophy--359.0**

Description:

Congenital Muscular Dystrophy is a disease of the muscles, present at birth and manifested in the infant by low muscle tone. All muscular dystrophies are genetically determined; however the term congenital muscular dystrophy is used to encompass several distinct diseases with a common characteristic of severe involvement at birth.

Effects/Prognosis:

Infants often have contractures or arthrogyposis (multiple congenital contractures). Head control is poor. Facial muscles may be mildly involved. The prognosis is variable; the disease may progress or stay the same.

**Other Myopathies--359.8**

Description:

Myopathy is a disease or abnormal condition of striated muscle. They encompass a widely varied group of muscle diseases which are characterized by weakness in infancy or childhood. Other myopathies include endocrine myopathies (thyroid and steroid-induced), and metabolic myopathies (potassium-related periodic paralysis, malignant hyperthermia, glycogenoses, mitochondrial myopathies, lipid myopathies, and vitamin E deficiency myopathies).

Effects/Prognosis:

The effects and prognosis of other myopathies are variable, depending on the specific underlying disease.

**Werding-Hoffman Syndrome--335.0  
(Infantile Spinal Muscular Atrophy)**

Description:

Werding-Hoffman disease is the severe infantile form of spinal muscular atrophy. Spinal muscular atrophies are degenerative diseases of motor neurons that begin in fetal life and continue to be progressive in infancy and childhood.

Effects/Prognosis:

Affected infants have severe hypotonia and generalized weakness. Infants who are symptomatic at birth may have respiratory distress and are unable to feed. Most infants demonstrate symptoms by six months of age. The disease is progressive, and two thirds of severely involved infants die by two years of age.

**Spinal Cord Injury, NOS--952.9**

Description:

Spinal cord injury is a trauma to the spinal cord during the birth process or afterwards. Strong traction exerted during delivery may produce fracture and separation of the vertebrae. Transection of the cord may occur with or without vertebral fractures.

Effects/Prognosis:

Effects are variable, depending on the level and location of the lesion. There may be loss of sensation and paralysis below the level of injury. If the injury is severe, the infant may deteriorate rapidly to death within several hours. The course may be protracted with symptoms and signs appearing at birth or later in the first week; immobility and associated brachial plexus injuries may not be recognized for several days. Treatment of survivors of spinal cord injury is supportive, and they often remain permanently injured.

**Lobster Claw --755.58 (Hand)**

Description:

Lobster claw is a deformity of the extremities which causes deep clefts in the anterior part of the hand.

Effects/Prognosis:

Fingers may have various degrees of syndactyly (fingers joined together). The prognosis is good if only one extremity is involved. The prognosis may be poor if multiple congenital anomalies are present.

**Arthrogryposis--728.3**

Description:

Arthrogryposis is not a disease, but is a descriptive term that signifies multiple congenital contractures. Multiple contractures around the joints of the arms and legs result in wasting of the muscles and loss of function. Involvement ranges from mild deformities to deformities which make functioning almost impossible.

Effects/Prognosis:

The prognosis is variable, depending on the underlying cause.

**Phocomelia (absence of limb)--755.4**

Description:

Phocomelia is a congenital malformation where the proximal portions of the extremities are poorly developed or absent. The hands and feet may be attached to the trunk directly or by means of a poorly formed bone. In complete phocomelia, the hand or foot seems to spring directly from the trunk.

Effects/Prognosis:

Severe deformities of the extremities are often associated with other malformations incompatible with life. The prognosis is variable, depending on the severity of the involvement and associated defects.

**Spina Bifida w/o hydrocephalus (unspecified region)--741.90**

Description:

Spina Bifida is a disorder of early fetal development resulting in failure of the spinal cord to fuse properly. Spina bifida occulta is the least serious form, where there is an opening in the spine but no protrusion of membranes, nerves or spinal cord. This form does not usually cause loss of body function. Meningocele is the protrusion of the membrane-like coverings of the spinal cord and nerves. Myelomeningocele is the most severe type of spina bifida, where a sac containing spinal cord and nerves protrudes through the defect in the vertebrae.

Effects/Prognosis:

Depending on the location and severity of the spinal lesion, some or all of the functions made possible by a normal spinal cord and nerves may be decreased or absent below the spina bifida. Spina bifida may affect muscle control, movement and strength; sensation in the legs and lower body; urinary and bowel function; and neurological function.

**Spina Bifida with hydrocephalus (unspecified region)--741.00**

Description:

Spina bifida is a disorder of early fetal development resulting in failure of the spinal cord to fuse properly. Please refer to spina bifida w/o hydrocephalus, 741.90 for a definition of spina bifida. Hydrocephalus develops in some cases with spina bifida when the

normal flow of cerebrospinal fluid is blocked and becomes trapped within the spaces which lie inside the brain.

Effects/Prognosis:

Depending on the location and severity of the spinal lesion, some or all of the functions made possible by a normal spinal cord and nerves may be decreased or absent below the level of the spina bifida. The prognosis is variable, depending on the level of the lesion and how much of the spinal cord is involved. Hydrocephalus usually requires some form of neurological shunt placement to drain cerebrospinal fluid.

### **III. Central Nervous System (CNS) Abnormalities**

#### **Infantile Cerebral Palsy (Not otherwise specified-Nos)- - 343.9**

Description:

Cerebral palsy is a static encephalopathy (a generalized disorder of cerebral function) resulting from injury to the brain during its early (fetal, perinatal, and early childhood) stages of development. Cerebral palsy is a problem that involves the brain's ability to control the muscles; muscle and nerve function is essentially normal. Cerebral palsy is categorized by a description of the resultant motor handicap: *physiologic* classification identifies the major motor manifestation, *topographic* taxonomy indicates the involved extremities.

*Physiologic*- spasticity (muscle stiffness - hypertonia) present in 60% of all cases of CP  
dyskinesia (involuntary movements) present in approximately 20% of all cases of CP  
athetosis – slow writhing movements; choreoathetosis – abrupt and jerky movements; and  
dystonia – slow, rhythmic movements  
ataxia (a broad based, lurching gait with primary balance difficulties) occurs by itself in about 1% of all CP.

*Topographic*-Diplegia – involvement of the trunk and all four extremities (the legs more so than the arms)

Hemiplegia – involvement of one side of the body only

Paraplegia – involvement of the legs only

Quadriplegia – involvement of both arms, both legs, the head, and the trunk

Monoplegia – involvement of one extremity

Triplegia – involvement of three extremities

Effects/ Prognosis:

Some children have barely detectable problems, while others have severe disabilities. Difficulties in mobility and communication are the major functional manifestations. There also may be associated problems with cognition, vision, and behavioral responses. Hearing impairment, seizures, constipation, and feeding difficulties can be accompanying health problems. Given the comprehensive care they require, children with CP can look forward to an average life span.

#### **Infantile Spasms without Intractable Epilepsy – 345.60 with intractable Epilepsy – 345.61**

Description:

Infantile Spasms are brief symmetrical contractions of the muscles of the neck, trunk, and extremities resulting in a jackknifing of the body. The character of the seizure depends on

whether the flexor or extensor muscles are predominately affected and the particular muscle groups involved. Infantile Spasms usually begin between the ages of 4 and 8 months and frequently emerge as a new development in a series of neurological abnormalities. Seizure activity typically occurs in clusters and tends to develop when the child is drowsy or immediately upon awakening. Eye movements and a pre- or post-spasm “cry” frequently accompany the seizure episodes. The most common EEG finding is hypsarhythmia; a continuous disorganized pattern of high voltage slow waves and spikes. ACTH and corticosteroids are the present treatment options, however, although there is often an improvement in the social interaction of the infant when spasms are controlled, there is no clear evidence that ACTH treatment improves the long-term outcome in terms of mental retardation. Infantile Spasms will subside in approximately one year in about 25% of the cases; and in two years in another 25% of the cases. The spasms may last 5 years or more and may be replaced by other types of seizure activity.

#### Effects/Prognosis:

Infantile Spasms are typically classified into two categories cryptogenic – normal pre-seizure health history, normal neurological examination and CT scan (10 –20% of Infantile Spasms are classified as cryptogenic and children with this subtype have a good prognosis).

Symptomatic – abnormal prenatal, postnatal, and postnatal factors including hypoxic-ischemic encephalopathy, congenital infections, inborn errors of metabolism, neurocutaneous syndromes, cytoarchitectural abnormalities, prematurity, Central Nervous System infections, and head traumas. Children with Symptomatic Infantile Spasms have an 80-90% risk of mild to severe mental retardation, depending on the severity of the neurological abnormalities before seizures appeared. Children with Infantile Spasms typically have delayed psychosocial development, and motor deficits such as spasticity and hypotonia. Microcephaly, cortical blindness and/or deafness, and a variety of other central nervous system (CNS) deficits are also present. Usually these problems are present in differing degrees prior to the onset of Infantile Spasms. The presence or absence of certain risk factors can significantly alter the prognosis. Death occurs in approximately 29% of children with Infantile Spasms.

### **Encephalocele—742.0**

#### Description:

An encephalocele is a neural tube defect resulting in the herniation of the meninges and portions of the brain ( cerebral cortex, cerebellum, or portions of the brain stem) through a bony midline defect in the skull, most commonly in the occipital region. The neural tissue within an encephalocele is often abnormal. This condition is one of two major forms of dysraphism (defective fusion of parts that usually unite). The first form, a cranial meningocele, is less severe and consists of a meningeal sac only.

#### Effects/Prognosis:

The amount of compromised and deformed neural tissue determines the extent of cerebral dysfunction and the resultant disabilities. Even brain tissue not extending into the encephalocele may be structurally and functionally abnormal. The following problems are seen: hydrocephalus, microcephaly, motor delays with weakness and/or spasticity, ataxia, seizures, and visual problems.

## **Microcephalus—742.1**

### Description:

Microcephaly is a congenital abnormality of the central nervous system where the head circumference measures more than three standard deviations below the mean for age and sex. Microcephaly is divided into two main groups: primary or genetic and secondary or nongenetic. Primary microcephaly refers to a group of conditions that are associated with specific genetic syndromes (Down Syndrome, Cri-du-chat, Cornelia de Lange, Edward-18-trisomy, Rubinstein-Taybi, Smith-Lemli, Optiz); usually have no other malformations, and follow a mendelian pattern of inheritance (autosomal recessive, autosomal dominant). Secondary microcephaly results from a large number of noxious agents that may affect the fetus in utero or the infant during periods of rapid brain growth, particularly the first two years of life (radiation, drugs, congenital infections, meningitis, encephalitis, malnutrition, etc.). Occasionally, microcephaly is due to premature closure of the cranial sutures (craniosynostosis) but more often is the result of micrencephaly (a small brain).

### Effects/Prognosis:

The clinical manifestations and degree of central nervous system (CNS) dysfunction vary, but there is a correlation between the severity of the microcephaly and the degree of mental retardation. Almost 90% of children with microcephaly will have mental retardation. Milder decreases in head size have been associated with learning disabilities and language disorders.

## **Reduction deformities of the brain - - 742.2**

### **Holoprosencephaly**

#### Description:

An anterior midline defect which occurs during early fetal development (before 23 weeks gestation) of the midface and the forebrain. The consequences of this defect are varying degrees of malformations in midline facial development, and in brain development and function. The incidence is 6-12/100,000 live births and, although the cause is unknown, the condition is sometimes seen in conjunction with chromosomal anomalies and as an autosomal dominant and autosomal recessive defect. It is also seen in children of diabetic mothers and as a result of congenital infections (CMV, toxoplasmosis, and syphilis). Holoprosencephaly is categorized into 3 types according to clinical features:

1. Alobar – anophthalmia (congenital absence of one or both eyes), cyclopia, median and bilateral cleft lip and palate, microcephaly, severe mental deficiency, apneic spells, seizures, death;
2. Semilobar -- orbital hypotelorism, microphthalmia, coloboma, normal lip and palate, absence of philtrum, median cleft lip, flat nose, single-nostril nose, mild to severely mentally retarded;
- and 3. Lobar—normal face, single maxillary incisor, minimal handicap, mild to severely mentally retarded.

#### Effects/Prognosis:

The prognosis is dependent on the severity of the involvement; although most affected individuals die before 6 months of age. Mildly affected individuals may live to adulthood. The degree of facial malformation is usually predictive of brain malformation. This condition is considered the most devastating of the anterior midline defects. Complications may include endocrine abnormalities such as hypopituitarism, ACTH-adrenal axis failure, and diabetes insipidus. An anterior midline defect which

occurs during early fetal development (before 23 weeks gestation) of the midface and the forebrain. The consequences of this defect are varying degrees of malformations in midline facial development, and in brain development and function. The incidence is 6-12/100,000 live births and, although the cause is unknown, the condition is sometimes seen in conjunction with chromosomal anomalies and as an autosomal dominant and autosomal recessive defect. It is also seen in children of diabetic mothers and as a result of congenital infections (cytomegalovirus (CMV), toxoplasmosis and syphilis).

Effects/Prognosis:

The prognosis is dependent on the severity of the involvement; although most affected individuals die before 6 months of age. Mildly affected individuals may live to adulthood. The degree of facial malformation is usually predictive of brain malformation. This condition is considered the most devastating of the anterior midline defects. Complications may include endocrine abnormalities such as hypopituitarism, ACTH-adrenal axis failure, and diabetes insipidus.

### **Lissencephaly**

Description:

A disorder of neuronal migration characterized by the absence of sulcation of the cerebral hemispheres resulting in a “smooth brain”. An insult before 12 weeks gestational age prevents successive waves of migrating neurons from reaching the cerebral cortex. This disorder is associated with various syndromes such as, *Miller-Dieker*, *Walker-Warburg*, *HARD+/-E Syndrome*. The following abnormalities are seen depending on the clinical subtype effecting the individual: open Sylvian fossa, absent or hypoplastic corpus callosum, large cavum septi pellucidi, small midline calcifications in the region of the third ventricle, microcephaly, high wrinkled forehead, small nose with anteverted nostrils, micrognathia, slanted palpebral fissures, low-set and/or posteriorly angulated auricles, late eruption of primary teeth, cryptorchidism, pilonidal sinus, polydactyly or syndactyly, and transverse palmar crease, cataracts, hypoplasia of optic nerve, microphthalmia, retinal dysplasia, hydrocephalus, congenital heart disease, duodenal atresia, renal agenesis.

Effects/Prognosis:

This condition may result in symptoms of failure to thrive, repeated aspiration pneumonia, hypotonia, or rigidity and opisthotonos, infantile spasms or other seizure activity, and severe mental retardation. Infants may exhibit brief visual fixation, smiling and nonspecific responses to stimulation. Developmental skills are minimal, and death usually occurs before 2 years of age.

### **Congenital Hydrocephalus—742.3**

Description:

Hydrocephalus is a condition that results from impaired circulation and absorption of cerebral spinal fluid (CSF) or, in rare circumstances, from increased production by a choroid plexus papilloma within the intracranial cavity. Hydrocephalus can be the result of obstruction within the ventricular system (obstructive or noncommunicating hydrocephalus), or the result of obliteration or malfunction of the absorption sites, i.e., the subarachnoid cisterns or the arachnoid villa (nonobstructive or communicating

hydrocephalus). Hydrocephalus is termed “congenital” when it exists at birth, or “acquired” when it occurs as the result of injury to the brain after birth.

Effects/Prognosis:

When there is an excessive accumulation of CSF fluid in the ventricular system, the resultant pressure (intracranial pressure) leads to various symptoms depending on the age of the child, whether or not the cranial sutures have fused, and the treatment rendered. A frequent surgical treatment is the placement of a ventriculoperitoneal shunt, which diverts CSF from a lateral ventricle to the peritoneal cavity. Prognosis depends on the cause of the dilated ventricles as opposed to the size of the cortical mantle at the time of operative intervention. There is an increased risk of developmental disabilities including: a reduced mean intelligence quotient, particularly for performance tasks; abnormalities in memory function; visual problems such as strabismus, visual spatial abnormalities, visual field defects, optic atrophy and aggressive and delinquent behavior in some children.

**Cystic Periventricular Leukomalacia (CPVL)—348.8**

Description:

Periventricular Leukomalacia is a softening of the white matter of the brain in the area of the ventricles due to hypoxic ischemic injury. Intraventricular hemorrhage in the premature infant is often a factor in the development of necrosis of the periventricular white matter and the resulting cystic formation

Effects/Prognosis:

Babies with CPVL are at a high risk for developmental abnormalities. The degree of white matter necrosis influences the severity of the mental and/or motor problems that result. These abnormalities may include: spastic diplegia (legs more involved than arms); delays and qualitative problems in motor development; slow mental development; problems with hearing or vision; seizures; attention deficits; poor coordination or balance; problems with eye-hand coordination; learning disabilities and behavioral difficulties.

**Intraventricular Hemorrhage (grade IV) - -772.1**

Description:

Intraventricular Hemorrhage (IVH) is a bleeding in the tissue surrounding the ventricles of the brain, most common in premature infants. The incidence of IVH increases with decreasing birth weight, with 80-90% of the cases occurring between birth and the 3<sup>rd</sup> day of life. There are four levels of hemorrhage that have been defined as follows:

Grade I- bleeding is confined to the subependymal matrix

Grade II- indicates intraventricular bleeding

Grade III- includes grade II plus intraventricular dilatation

Grade IV- includes grade III plus intracerebral bleeding

Effects/Prognosis:

Babies with grade IV bleeds frequently develop serious ongoing neurological problems although the degree of neurological impairment may be related to a combination of factors such as the initial hypoxic or other insult, the hemorrhage itself, increased intracranial pressure, or the ventricular dilatation following the hemorrhage. Ten to fifteen % of low birth weight infants with IVH develop hydrocephalus. Leukomalacia and porencephalic cysts are other common complications. The following problems may

develop: fine and gross motor delays, cerebral palsy, vision and hearing impairments, and nongenetic.

### **Kernicterus—774.7**

#### Description:

Kernicterus is damage to particular parts of the brain (basal ganglia and brainstem nuclei) due to the accumulation of high levels of unconjugated bilirubin. An increase in bilirubin production or a decrease in bilirubin excretion or both will result in neonatal hyperbilirubinemia (bilirubin concentrations greater than 10 mg/dL in premature infants or 15mg/dL in fullterm infants). Excessive bilirubin accumulation from any cause can produce kernicterus, especially in the preterm or sick newborn. Some possible causes of neonatal hyperbilirubinemia are as follows: fetal-maternal blood group incompatibility, extravascular blood such as pulmonary or cerebral hemorrhage, polycythemia such as fetal to fetal transfusion, obstructive disorders such as a band or tumor, sepsis, intrauterine infection, respiratory distress syndrome, asphyxia, child of a diabetic mother.

#### Effects/Prognosis:

Hyperbilirubinemia is treated by early, frequent feedings, phototherapy, and exchange transfusions in an effort to prevent kernicterus. It is also vital to diagnose and treat the underlying cause of the hyperbilirubinemia to prevent or lessen the serious consequences of kernicterus. Kernicterus can result in following problems: opisthotonos, muscular rigidity, seizures, hypotonia, bilateral choreoathetosis with involuntary muscle spasm, extrapyramidal signs, mental deficiency, dysarthric speech, high frequency hearing loss, squints and defective upward movement of the eyes, ataxia. In mildly affected infants the syndrome may be characterized only by mild to moderate neuromuscular incoordination, partial deafness or minimal brain dysfunction occurring singly or in combination.

### **Multiple anomalies of brain (Nos.)—742.4**

#### **Congenital cerebral cyst**

(See below, True Porencephalic Cyst)

#### **Macrocephaly**

##### Description:

Macrocephaly is an occipitofrontal head circumference more than 2 standard deviations above the mean for age. The most frequent causes of macrocephaly are mass lesions (porencephalic cysts, tumors, subdural hematomas, etc.), megalencephaly, and hydrocephalus. Macrocephaly can be familial, or associated with a number of syndromes, and several storage diseases.

##### Effects/Prognosis:

Most significant degrees of macrocephaly are likely to indicate the presence of neurodevelopmental disorders. The effects and prognosis will depend on the underlying condition responsible for the increase in head circumference and the availability of prompt and effective treatment.

## **Megalencephaly**

### Description:

Megalencephaly is an abnormally large, oftentimes, malfunctioning brain.

### Effects/Prognosis:

Megalencephaly may be a familiar trait not associated with any other deficiencies, but usually is an indication of underlying medical problems such as epilepsy and other neurological conditions.

## **Porencephaly**

### Description:

Porencephaly is a fluid-filled cyst or cavity within the cerebrum. There are two types of porencephalic cysts:

- 1.) True Porencephalic Cysts: These are cysts that occur as a result of faulty embryonic neurodevelopment. They typically communicate with the ventricles, cerebral cortical surface, and/or subarachnoid space.

### Effects/Prognosis:

True Porencephalic Cysts are associated with more severe neurologic manifestations. Some of the possible manifestations are as follows: hypotonia, seizure disorder, developmental delay, mental retardation, mild to severe motor dysfunction, failure to thrive, optic atrophy, delayed limb growth, hydrocephalus, supranuclear bulbar palsy.

- 2.) Pseudoporencephalic Cysts typically arise after a well-defined destructive event (of normal brain tissue) such as vascular disruption or infection occurring late in fetal or early infantile life (intraventricular hemorrhage, periventricular leukomalacia, congenital infections). This event leads to a cavitation of the necrotic region and cyst formation within the parenchyma of the cerebral hemispheres. These cysts usually do not communicate with other structures, tend to be unilateral, and are typically not associated with other disorders.

### Effects/Prognosis:

Pseudoporencephalic Cysts are associated with hemiparesis and focal seizures in the first year of life. Prognosis is variable; some children develop only minor neurological signs and have normal intelligence.

## **IV. Hearing, Vision and Communication Disorders**

### **Retinopathy of Prematurity—362.21 (grades 4 and 5)**

#### Description:

Retinopathy of prematurity is also known as Terry disease. This is an eye disease that is a major cause of blindness. Retinopathy of prematurity (ROP) occurs primarily in premature infants and is more severe with decreasing birth weight. ROP results from abnormal development of the retina (the light sensitive lining of the eye) in premature babies. It occurs when abnormal blood vessels and scar tissue form at the edge of the normal retinal blood supply. The abnormal retina then has a damaging demand for oxygen.

ROP is a progressive disease that starts slowly, usually between the fourth to tenth week of life. Progression may be slow or rapid through Stages 1-5 or the disease may stop at the early stages and disappear completely. Not all premature infants develop ROP. The two critical factors for predicting who will develop ROP are birthweight less than 1500 grams and gestational age at birth less than 32 weeks. High oxygen levels may exacerbate ROP but do not cause the disease. Stages 4 and 5 reflect more severe involvement than the earlier stages.

Stage 4 ROP is caused by the scar tissue formed in Stages 1 through 3 pulling on the retina and causing it to separate from the wall of the eyeball. Stage 4 is subdivided, depending on the location of the detachment. In stage 4A, the detachment is partial and outside the macula (the area of central vision) and it may or may not affect the infant's vision. Stage 4B is characterized by partial detachment involving the macula. Stage 5 ROP involves a complete retinal detachment. Infants with Stage 5 ROP have essentially no useful vision in that eye.

Effects/Prognosis:

Stages 1 and 2 and Stage 3/mild require monitoring. Treatment is instituted at Stage 3/moderate or severe because these infants have a 50% chance of proceeding to Stage 4 or 5 and possible blindness. For Stage 4A, the chance for usable vision is relatively good if the retina reattaches. Stage 4B generally results in a more limited prospect for usable vision due to the macular involvement. Treatment options at Stage 5 involve surgery to attempt to reattach the retina. Some vision may be recovered by this surgery but the individual will most likely be legally blind in the involved eye.

**Conductive Hearing Loss (Nos.)—389.00**

Description:

Conductive hearing loss refers to hearing loss arising from failure of sound pressure to reach the cochlea (inner ear) through the normal air conduction channels (outer and/or middle ear). This type of hearing loss results from a problem in the outer and/or middle ear space and can range from mild to moderate-severe in degree. Causative factors range from fluid in the middle ear space to congenital malformations of the outer and/or middle ears. Depending on the cause, conductive hearing loss may fluctuate. In a conductive hearing loss, hearing sensitivity will be impaired via the air conduction (outer + middle + inner ear) pathway and normal via the bone conduction (inner ear) pathway.

Effects/Prognosis:

Effects of conductive hearing loss are dependent on the extent and duration of the hearing loss. For example, with a 30 dB HL (mild) hearing loss, 25-40% of the speech signal may be missed. This can result in difficulty hearing consonant sounds. The individual will generally have to expend greater energy to listen, resulting in fatigue. Typical symptoms include "not paying attention" and "daydreaming." Depending on the cause, conductive hearing loss may be treated and cured through medical and/or surgical means. If the hearing loss cannot be resolved medically, amplification can be pursued if the individual is otologically cleared. Periodic audiological monitoring of hearing levels and middle ear function will be needed. Speech/language consultation may also be required.

It should be noted that the Early Intervention Program regulations (Section 69-4.3(e)(5)) specify that a hearing impairment qualifying as a diagnosed condition with a high probability of developmental delay is a diagnosed hearing loss that cannot be

corrected with treatment or surgery. Thus, for the purposes of this diagnostic category, only conductive hearing losses that are not amenable to resolution through medical or surgical means, are chronic in nature and/or have an impact on other areas of development, particularly speech/language/communication development, constitute diagnosed conditions with a high probability of developmental delay for the purposes of eligibility in the Early Intervention Program. Consistent with the regulatory language, an occasional or transient conductive hearing loss occurring in isolation, i.e., without concomitant delays in other developmental domains, would typically be managed through the child's primary medical care provider.

### **Sensorineural Hearing Loss (Nos.)—389.10**

#### Description:

Sensorineural hearing loss is a hearing loss resulting from a pathological condition in the inner ear (cochlea) or along the nerve pathway from the inner ear to the brainstem (cranial nerve 8); it may be cochlear or retrocochlear depending on the site of the lesion. Sensorineural hearing loss may range from mild to severe to profound in degree. Causes are varied and include congenital abnormality in the auditory nerve, damage to the cochlea (e.g. from certain antibiotics such as gentamycin) and diseases such as meningitis. Certain syndromes are associated with sensorineural hearing loss. High risk factors for sensorineural hearing loss include, but are not limited to: low birth weight (less than 1500 grams), anoxia, jaundice, cranial defects, congenital viral infections (e.g. rubella) and family history of hearing loss.

#### Effects/Prognosis:

Effects of sensorineural hearing loss depend on numerous factors, including the degree (extent) of hearing loss, age at onset of hearing loss, age at identification of the hearing loss and amplification (personal hearing aids, FM system) history. For example, an individual with a moderate (41-55 dB HL) sensorineural hearing loss can miss 75-80% of the speech signal without amplification. Effects on speech/language skills may include delayed or defective syntax, limited vocabulary, imperfect speech production and an atonal voice quality. With a severe hearing loss (71-90 dB HL), the individual may hear loud voices about one foot away from the ear. Optimal amplification will provide access to environmental sounds and to many speech sounds. Individuals with profound hearing loss (91 dB HL or more) may rely on vision as the primary avenue for communication and learning. If the loss is of prelingual (before speech development) onset, oral language and speech may not develop or will be severely delayed. Prognosis varies depending on multiple factors, including consistent amplification and intervention emphasizing development of language, speech and auditory skills. Regular audiological consultation to monitor hearing levels and amplification will be required.

### **Mixed Conductive and Sensorineural Hearing Loss—389.20**

#### Description:

Mixed hearing loss is a combination of conductive (outer and/or middle ear) and sensorineural (inner ear) hearing loss occurring simultaneously. The hearing loss may range from mild to severe to profound in degree.

Effects/Prognosis:

Effects of the hearing loss depend on numerous factors, described above. Management of the hearing loss will include medical consultation regarding the conductive (outer and/or middle ear) component and may include amplification to address the remaining hearing loss, once the individual is otologically cleared. Regular audiological consultation to monitor hearing levels, middle ear status and any amplification needs will be required. Speech/language consultation may also be required.

**Unspecified anomalies of the ear with hearing impairment—744.00**

Description:

Anomalies of the ear generally include external ear changes that make these syndromes easier to diagnose. The hearing loss may be congenital or slowly progressive. Syndromes include, but are not limited to: 1. atresia (closure) of the external auditory canal with conductive hearing loss; 2. ear malformations, persistent periauricular pits (depressions around the external ear), sinuses or nodules, and mixed hearing loss; 3. preauricular pits, persistent branchial (Gill) clefts or fistulas, and sensorineural hearing loss; 4. malformed low-set ears and conductive hearing loss; 5. small external ear, meatal (ear canal) atresia and conductive hearing loss; and 6. lop ears, small lower jaw, and hearing impairment of mixed type.

When a middle ear deformity is present, the stapes, which develops from different embryological origins than the malleus and incus, is usually involved.

Other structural lesions producing hearing impairment involving congenital inner ear anomalies have been described. These are: 1. The Michel type 2. The Mondini-Alexander type 3. The Bing-Siebenmann type 4. The Scheibe, or cochleo-saccular type (which is the most common type of congenital abnormality and accounts for 70% of cases) 5. The Siebenmann type and 6. Type VI exhibits microtia (abnormally small external ear) and atresia (absence or closure) of the external meatus (ear canal).

Effects/Prognosis:

Effects are variable and dependent on numerous factors including the extent of hearing loss. Otologic management will be required to address the medical aspects and audiological management will be required to maximize the use of the individual's residual hearing. Speech/language consultation may also be required.

**Dyspraxia Syndrome—315.40**

Description:

Dyspraxia is a less severe form of apraxia. Apraxia is defined as a disruption in the ability to transmit or express a motor response along a specific modality; involves disruption of voluntary or purposeful programming of muscular movements while involuntary movements remain intact; characterized by difficulty in articulation of speech, formation of letters in writing, or in movements of gesture and pantomime. In speech, a non-linguistic sensorimotor disorder of articulation characterized by impaired capacity to program the position of speech musculature and the sequencing of muscle movements (respiratory, laryngeal, oral) for the volitional production of phonemes. Synonymous terms include: oral, speech or verbal apraxia.

Effects/Prognosis:

Variable, depending on the severity of involvement. If severely affected, the treatment may include accessing other modes of communication, e.g. sign language or an augmentative communication device.

**Blindness, both eyes—369.00**

Description:

A person is termed blind when there is corrected visual acuity less than 20/200 in the better eye. It has been recommended that the definition of the term blind be restricted to the absence of light perception and that “visual impairment” and “low vision” be extended to describe persons with vision less than 20/200 but who retain light perception.

Effects/Prognosis:

Effects vary depending on such factors as the onset of blindness. Individuals with congenital blindness (born blind) may be developmentally delayed because the process of learning through the visual channel has been severely limited. Those with adventitious blindness (blindness occurring after birth) may be developmentally similar to others in their age group, depending on when the vision loss occurred. Blind infants may show delays in the areas of gross motor development related to the development of locomotion, in prehension (physical grasp) skills and in the development of attachment.

**Blindness, one eye, low vision other eye—369.10**

Description:

See definition for blindness, above. Low vision generally refers to severe visual impairment, not necessarily limited to distance vision. Low vision applies to all individuals who are unable to read the newspaper at a normal viewing distance, even with the aid of corrective lenses. The rate of visual handicaps is higher among individuals with multiple handicaps.

Effects/Prognosis:

Effects depend on the age of onset and amount of residual vision. Screening for potential visual abnormalities during infancy or early childhood is important as this is the optimal time for preventing or minimizing visual impairments. Signs of eye problems include frequent squinting or rubbing, of the eyes, lack of attention or irritability.

**Low vision both eyes (moderate to severe)—369.20**

Description:

See definition for low vision, above.

Effects/Prognosis:

See information under low vision (369.10), above.

**Optic nerve coloboma (bilateral), congenital—743.57**

Description:

Colobomata are areas of absent tissue, and are found where fetal clefts or fissures fail to close. In the eye, these may involve portions of the optic disc (the circular tip of the optic nerve).

Effects/Prognosis:

Involvement of the optic disc results in depressed central vision. Depending on the extent and location of the coloboma, there may be decreased visual acuity, nystagmus, strabismus, photophobia and a loss of visual fields. Treatment options include cosmetic contact lenses and/or sunglasses for colobomas of the iris. Optical aids may be helpful. When a coloboma of some part of the inner eye is suspected, visual fields measurement is suggested.

**Optic nerve coloboma (bilateral), acquired—377.23**

Description:

A coloboma is a defect in the eye, usually a fissure or cleft of the iris, ciliary body (thickened part of vascular tunic of the eye between the base of the iris and the anterior part of the choroid) or choroid (dark brown vascular coat of the eye between the sclera and the retina, extending from the ora serrata to the optic nerve; consists of blood vessels united by connective tissue). This condition may be acquired as a result of surgery.

Effects/Prognosis:

See above.

**Aniridia—743.45**

Description:

Aniridia is congenital absence of all or part of the iris. This defect is usually accompanied by photophobia, nystagmus and defective vision. Other associated conditions include glaucoma, progressive corneal degenerative changes, cataracts, macular hypoplasia and optic nerve hypoplasia. Transmission of this condition may be familial or sporadic. Sporadic aniridia is associated with Wilms tumor in 1/70 patients. In Aniridia-Wilms Tumor Association, abnormalities include moderate to severe mental deficiency in most patients, growth deficiency and microcephaly in one half of patients, craniofacial abnormalities, aniridia in most patients and Wilms tumor (a malignancy of the kidney) in one half of patients.

Effects/Prognosis:

It is estimated that one third of individuals with sporadic aniridia develop Wilms tumor, while 50% of those with combined aniridia, genitourinary anomalies, and mental retardation develop Wilms tumor. Effects of this disorder depend on the severity of the deficits. Associated eye abnormalities in addition to aniridia include congenital cataracts, nystagmus, ptosis (upper eyelid droops below its normal level) and blindness. With aniridia, there is usually decreased visual acuity (circa 20/200), photophobia, possible nystagmus, cataracts, displaced lens, and underdeveloped retina; visual fields are usually normal, unless glaucoma develops. Because the macula (the most sensitive part of the retina) doesn't fully develop ("macular hypoplasia"), reduced vision occurs. The macula is used for fine vision, such as for reading. Treatment strategies include pinhole contact lenses, tinted lenses and/or sunglasses, corrections for refractive errors, optical aids, lower illumination levels to control glare. Magnification may also be helpful. Long-term prognosis is poor if glaucoma develops.

## **Albinism—270.2**

### Description:

Albinism is a genetic absence of pigment of the skin, hair, and eyes, or eyes only, resulting from a metabolic defect. Visual impairment (refractive errors), strabismus (cross eye, squint), nystagmus (involuntary eye movements) and photosensitivity are common.

### Effects/Prognosis:

Due to absence of normal protection by melanin in the skin, individuals with albinism are predisposed to damage from ultraviolet light. They require use of sunscreen during exposure to sunlight. Eye abnormalities require ophthalmological evaluation and treatment/ correction based on the diagnosed condition.

## **Visual deprivation nystagmus—379.53**

### Description:

Nystagmus is an oscillatory motion of the eyes that may be congenital or acquired. Congenital nystagmus is pendular (back and forth movements are at roughly the same speed) at rest, with irregular jerking when the eyes are deviated to the sides. It is usually associated with poor visual acuity and is thought to be due to failure of development of visual fixation in infancy. Congenital nystagmus often accompanies congenital visual impairment (e.g. corneal opacity, cataract, albinism, aniridia, optic atrophy, chorioretinitis).

Nystagmus may also involve jerk-type movements, in which there is a rapid movement in one direction followed by a slower recovery movement in the opposite direction. The character of the oscillation may change in different positions of gaze, and there may be a null point at which the nystagmus is minimal. Patients with a null point tend to maximize their vision by assuming a head position in which the nystagmus is least marked. This head-turning to position eyes at a null point is a natural and effective means of improving vision.

Nystagmus is classified according to the position of the eyes when it occurs. Grade I nystagmus occurs only when the eyes are directed toward the fast component; Grade II occurs when the eyes are also in their primary position; Grade III occurs even when the eyes are directed toward the slow component.

### Effects/Prognosis:

Reduced visual acuity is caused by the inability to maintain a steady fixation. Head nodding often accompanies congenital nystagmus. Patients with a null point tend to maximize their vision by assuming a head position in which the nystagmus is least marked. This head-turning to position eyes at a null point is a natural and effective means of improving vision. Certain types of jerky nystagmus (usually Grade I types) show spontaneous improvement in childhood (up to age 10). This type may also be amenable to muscle surgery (essentially, a repositioning of muscles to take advantage of the point of least nystagmus, or position of relative rest).

Nystagmus reduces vision more at a distance than at close range. Therefore, a child with nystagmus may hold objects close to see them and will do better on near visual acuity tests than on a wall chart test. Educationally, children with nystagmus may tend to lose their place in beginning reading instruction and may be helped through the use of a typoscope (card with a rectangular hole, to view one word or line at a time), or an

underliner (card or strip of paper to “underline” the line being read). As children with nystagmus mature, they seem to need these support devices less often.

## **V. Psychiatric/Emotional/Behavioral Disorders**

### **Infantile Autism active state--299.00**

#### Description:

Infantile autism usually becomes evident before 30 months of age and is characterized by a qualitative impairment in verbal and nonverbal communication, imaginative activity, and reciprocal social interactions.

#### Effects/Prognosis:

The most notable symptoms and signs, consequences of impaired communication and social reciprocity, are nondeveloped or poorly developed verbal and nonverbal communication skills, abnormalities in speech patterns, impaired ability to sustain a conversation, and abnormal social play. Stereotypic body movements, a marked need for sameness, narrow interests, and preoccupation with parts of the body are also frequent. Eye contact is minimal or absent. If speech is present, echolalia, pronomial reversal and other idiosyncratic language forms may predominate. Prognosis is guarded. Some children, especially those with language may become marginally self sufficient. A better prognosis is associated with higher intelligence, functional speech, and less bizarre symptoms and behavior. Symptoms often may change as children grow older.

### **Pervasive Developmental Disorder (PDD) --299.80**

#### Description:

Pervasive developmental disorder includes autism as its major diagnostic entity; pervasive developmental disorder *not otherwise specified* refers to children who have autistic features but do not formally qualify for that diagnosis. Some children have a qualitative impairment in the development of reciprocal social interaction and verbal and nonverbal communication but do not have the quantity of symptoms necessary for a diagnosis of autism. These individuals may be diagnosed as having a schizoid personality disorder or Asperger syndrome, which generally refers to a higher functioning form of autism, although this distinction remains somewhat controversial.

#### Effects/Prognosis:

Pervasive developmental disorder is a pattern of atypical development that can coexist with mental retardation. Children may be somewhat socially aware, but appear to others to be peculiar and eccentric. Prognosis for these individuals would be similar to that of those children with autism who have higher intelligence and functional speech.

### **Prolonged Post Traumatic Stress Disorder--309.81**

#### Description:

Post traumatic stress disorder (PTSD) is a psychophysiological syndrome which may follow trauma, either episodic (as in a single extremely stressful event like rape, fire, flood), prolonged (wartime events/conditions) or cumulative so called "strain trauma," (ongoing child abuse, incest, neglect). The symptoms and behavioral manifestations vary with the developmental level of the child.

Effects/Prognosis:

Very young children may present with what appear to be developmental delays and/or behavior and anxiety disorders. Symptoms can be grouped as hyperarousal (anxiety states, especially separation anxiety, hyperactivity, sleep disturbances, hypervigilance), hypoarousal (numbness, inattention, difficulty concentrating, "withdrawn" behavior, avoidant/phobic behavior) and reexperiencing (repetitive reenacting play).

**Emotional Disturbance of Childhood (Unspecified)--313.9**

Description:

The categories of emotional disorder that apply to children include three that are specific to children--overanxious disorder, avoidant disorder of childhood, and separation anxiety disorder; and a number from the adult nosology--obsessive compulsive disorders, phobic disorders, somatoform disorders, and depressive disorders.

Effects/Prognosis:

The symptoms of emotional disorders in very young children are frequently not as well differentiated as they are in adults. As a result it is sometimes difficult to categorize an emotional disorder in a child because there is no predominant type of symptom that colors the clinical picture or appears to be specifically related to functional impairment. Many children with emotional disorders grow up to be healthy adults, with the likely exceptions of those with definite childhood diagnoses of obsessive-compulsive, severe separation anxiety, and severe depressive disorders.

**Attention Deficit/Hyperactivity Disorder--combined type--314.01**

Note: texts dated 1996 and after do not give separate definitions and descriptions for Attention Deficit Disorder (ADD) with and without hyperactivity. The current terminology describes a "predominately inattentive type" and a "predominately hyperactive/impulsive type" and a "combined type".

Description:

Children with attention deficit/hyperactivity disorder (ADHD) commonly exhibit elements of both inattention and hyperactivity-impulsivity in varying degrees and combinations.

Effects/Prognosis:

Characteristics of this disorder may include poor ability to attend to a task, heightened distractibility, motoric overactivity and impulsivity. Children with attention deficit hyperactivity disorder may have difficulty following instructions and sustaining attention, shift rapidly from one uncompleted activity to another, talk excessively, intrude on others, often seem not to listen to what is being said, lose items regularly, and often engage in physically dangerous activities without considering possible consequences. A program that gives structure to a child's environment decreases the effects of the handicap. Although hyperactivity may be short-lived, other symptoms of ADHD may persist into later life.

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