2.0 Definition of Developmental Delay

Authority

34 C.F.R. 303.10, 303.21, 303.111

Purpose

The purpose of this policy statement is to assure that WV Birth to Three has in place a rigorous definition of developmental delay that includes the eligibility criteria and procedures, consistent with Sec. 303.10, 303.21, 303.111, 303.203(C), and 303.321 which will be used statewide to determine the eligibility of infants and toddlers in West Virginia to receive Part C early intervention services. Subject to parental consent, each child who is referred for eligibility or services at least 45 days prior to his/her third birthday, will be provided a timely, comprehensive multidisciplinary evaluation as defined below. If determined eligible, a multidisciplinary assessment of the child's unique strengths and a family directed assessment of the family's resources, priorities and concerns will be provided as further defined under 303.321 and WVBTT Policy 3.0 Evaluation and Assessment.

2.1 Policy

2.1.1 The determination of whether a child meets the eligibility criteria of WV Birth to Three must be made by an appropriately qualified multi-disciplinary evaluation/assessment team, in a nondiscriminatory manner. The multi-disciplinary evaluation/assessment team is responsible for assuring that evaluation documentation clearly reflects the child's initial and/or annual eligibility in accordance with each area of the WV Birth to Three eligibility definition. This documentation must be present in the child's record.

2.1.2 Procedures for Evaluation: In conducting the initial or annual evaluation for eligibility, no single procedure may be used as the sole criterion for determining the child's eligibility for services. In order to determine a child's initial and/or annual eligibility, the multi-disciplinary team must use informed clinical opinion, supported by multiple methods and strategies. While informed clinical opinion may be used to establish eligibility even when formal test results do not establish eligibility, in no case may informed clinical opinion be used to negate the results of formal test results used to establish eligibility. Evaluation procedures must include:

A. With parental permission, review of educational, medical, or other records including vision and hearing, and consultation with the child's primary health care provider (it is especially important to determine if the parents' health concerns about the child may be related to any other diagnosis or condition);

B. Review of developmental history;

C. Parent interview;

D. Administration and written results of appropriate screening and/or assessment diagnostic instruments and procedures selected so as to not be racially or culturally discriminatory. Unless clearly not feasible to do so, evaluations must be conducted in the native language of the child; and

E. Observation of the child within typical daily routines.

F. Identifying the child's level of functioning in each of the developmental areas in 2.1.3.

G. Gathering information from other sources such as family members, other caregivers, medical providers, social workers, and educators, if necessary, to understand the full scope of the child's unique strengths and needs.

2.1.3 Areas of development to be evaluated for all children:

A. Cognitive Development – how the child thinks, plays, and interacts with others and within his/her environment;

B. Physical Development (including motor, vision and hearing) –Motor development includes fine motor abilities (how a child uses his/her small muscles for eye-hand coordination, visual tracking, reaching for and grasping and releasing objects) and gross motor abilities (how a child uses his/her large muscles for rolling, crawling, walking, running and jumping);

C. Communication Development – how the child understands and expresses language;

D. Social or Emotional Development – how the child perceives himself/herself, interacts with others, copes with frustration, and expresses his/her emotions;

E. Adaptive Development – how the child performs routine activities such as dressing and eating.

2.1.4 In order to be eligible for WV Birth to Three, an infant or toddler must under three years of age and: be a resident of West Virginia; a Native American child residing on a reservation geographically located in West Virginia; a child who is homeless; or a ward of the state. In addition, the child must be demonstrating criteria that meets one or more of the following eligibility categories:

2.1.4.1 *A very substantial delay in one or more areas of development as documented through the methods in 2.1.2.*

A very substantial delay indicates that the child is demonstrating the equivalent of a 40% delay in functional abilities/developmental skills from what would be expected for a child of his/her age. This delay is not expected to resolve without the benefit of early intervention services. In addition to reporting formal assessment results, the MDT member is responsible for using informed clinical opinion and the methods identified in 2.2.1.2 to provide a written description of how the child's functional abilities represent a very substantial delay in one or more areas, from what would be expected for a child of his/her age (or adjusted age up to 24 months).

OR

2.1.4.2 *A substantial delay in <u>two or more</u> areas of development as documented through the methods in 2.1.2.*

A substantial delay indicates that the child is demonstrating the equivalent of a 25% delay in functional abilities/developmental skills from what would be expected for a child of his/her age. This delay is not expected to resolve without the benefit of early intervention services. In addition to reporting formal assessment results, the MDT member is responsible for using informed clinical opinion and the methods identified in 2.1.2 to provide a written description of how the child's functional abilities represent a substantial delay in two or more areas, from what would be expected for a child of his/her age (or adjusted age up to 24 months).

OR

2.1.4.3 *Substantially atypical development in <u>two or more</u> developmental areas for a child his/her age, even when evaluation does not document a 25% delay.*

This substantially atypical development is determined to likely result in developmental delay without the benefit of early intervention services. In addition to reporting formal assessment results, the MDT member is responsible for using informed clinical opinion and the methods identified in 2.1.2 to provide a written description of how the child's functional abilities are substantially atypical from what would be expected for a child of his/her age (or adjusted age up to 24 months), in two or more areas as identified in 2.1.3.

Children in this category may have patterns of development different from their peers, such as:

- Atypical sensory-motor development: muscle tone, reflex or postural reaction responses, oral-motor skills and sensory integration
- Atypical language or cognition: state regulation, attention span, perseveration, information processing
- Atypical emotional or social patterns: social responsiveness, affective development, attachment patterns, and self-targeted behaviors

OR

2.1.4.4 *A diagnosed physical or mental condition documented in writing by the child's primary care or specialty physician, which has a high probability of resulting in a developmental delay.*

These may include conditions listed below such as chromosomal abnormalities; genetic or congenital disorders; sensory impairments; inborn errors of metabolism nervous system disorders; congenital infections; severe attachment disorders; and disorders secondary to exposure to toxic substances, including fetal alcohol syndrome.

Other diagnoses may only be considered to be Established Conditions if the multi-disciplinary team has written documentation from the child's primary care or specialty physician that the diagnosis will likely result in substantial developmental delay that is not of a transient or short term nature. If a child has more than one established condition, all conditions are to be documented on the eligibility form. Diagnoses from 'Biological Risk Factors' list are not considered to be Established Conditions.

WV Birth to Three Recognized Established Conditions

CHROMOSOMAL ABNORMALITY /GENETIC DISORDERS	**INFECTIOUS DISEASE**
Angelman Syndrome	Congenital Rubella Syndrome
	Poliomyelitis
	TOXIC EXPOSURE
Cornelia De Lange Syndrome	Lead Exposure (postnatal) ∗ 15 McG/ml.
Cri-Du-Chat Syndrome	Fetal Alcohol Syndrome (FAS) (Prenatal)
Di George Syndrome	**NERVOUS SYSTEM**
Down Syndrome (Trisomy 21)	Ataxia
Fragile X Syndrome	Cerebral Palsy (Athetoid, Spastic, Spastic Dysplegia)
Other Deletion or Duplication of Chrom. 1 through 22	Cerebrovascular Accident (CVA, Stroke)
(Not X or Y)	Infantile Spasms
Prader-Willi	Intraventricular Hemorrhage (IVH), Grade III or IV
Smith Magenis Syndrome	Lennox-Gastaut Syndrome
Treacher Collins	

Trisomy 13 (Patau Syndrome) Trisomy 18 (Edwards Syndrome), E Trisomy Trisomy 8 Mosaicism Trisomy 9 Mosaicism Trisomy 9P William Syndrome (Chromosome 7 Deletion) **CONGENITAL DISORDER** Arthrogryposis Cleft Palate Spina Bifida (Myelomeningiocele) Microcephaly **INBORN ERROR OF METABOLISM** Hunter Syndrome (Mucopolysaccharidoses) Hurler-Scheie Syndrome Lesch-Nyhan Syndrome Maple Syrup Urine Disease (MSUD) Mucolipidosis Mucopolysaccharidosis (MPS) Smith Lemli-Opitz Tay Sachs Disease	Leukodystrophies (Degenerative Neurologic Disease) Mental Retardation Muscular Dystrophy Neural Tube Defects (include Spina Bifida, Anencephaly) Paralysis Spinal Cord Injury **SEVERE SENSORY IMPAIRMENT** Bilateral External Ear Anomalies Blindness Hearing Impairment Lebers Ameurosis Optic Nerve Atrophy Optic Nerve Hypoplasia Retinoblastoma Vision Impairment **SEVERE ATYPICAL DEVELOPMENTAL DISORDERS** Attachment Disorder Autistic Disorder Pervasive Developmental Disorder

OR

2.1.4.5 *Five or more risk categories, that when present in combination, are likely to result in substantial developmental delay if early intervention services are not provided, as defined in policy.*

In order to be eligible under the At-Risk category, the infant or toddler and their family must be experiencing <u>at least five</u> or more of the following twenty categories of risk factors. The MDT member is responsible for documenting the category and risk factors that are impacting the child. If a child is experiencing one of the listed biological risk factors and is also demonstrating a developmental delay as identified under 2.1.4.1 through 2.1.4.4, the child's primary eligibility will be identified under the developmental delay category.

WV Birth to Three At-Risk Categories

- **Low Birth Weight** (1500 gms. or less, considered up to 24 months of age)
- **Severe asphyxia** (5 min. APGAR < 5)
- **Small for Gestational Age** (less than 10th percentile)
- **Chronic Otitis Media** (physician diagnosis required)
- **Gestational Age** (child born at 32 weeks or less gestation) (considered up to 24 months of age)
- **Technology Dependent** (includes ventilator, g-tubes, alternate feeding) (does not include apnea monitors)
- **Child abuse or neglect substantiated by CPS**
- **Family Barrier To Accessing Support** (this factor may include any of the following barriers: a primary caregiver (parent) under age 18, a primary caregiver with educational level less than a high school degree, a family income level which qualifies for Federal assistance, no health insurance coverage, no permanent residence, or recent multiple changes in residence).
- **Serious Parental Concern** (Parent expresses serious concern about their child's possible developmental delay)
- **Primary Caregiver** (individual reports having a chronic mental illness, developmental disability or mental retardation)
- **Family Support Stressor** (This factor may include stressors such as single parent with no other adult in household, lack of social support, physical or social isolation, primary caregiver with 4 or more preschool age children, primary caregiver with another child who has a diagnosed disability).
- **Chromosomal Abnormality/ Genetic Disorder** (See examples from the list of biological risk factors)
- **Congenital Disorder** (from the list of biological factors)
- **Severe Sensory Impairment** (from list of biological factors)
- **Nervous System Impairment** (from list of biological factors)
- **Inborn Error of Metabolism** (from list of biological factors)
- **Infectious Disease** (from list of biological factors)
- **Chronic Medical Illness** (from list of biological factors)
- **Perinatal Factor** (from the list of biological factors, not otherwise included here)
- **Toxic Exposure** (from list of biological factors)

BIOLOGICAL RISK FACTORS THAT CAN BE CONSIDERED UNDER THE AT-RISK CATEGORIES

CHROMOSOMAL ABNORMAILITY/GENETICS DISORDERS	**NERVOUS SYSTEM**
Achondroplasia	Closed Head Injury
Ehlers-Danlos	Congenital Malformation of the Brain
Klinefelter (XXY) Syndrome	Encephalocele
Marfan Syndrome	Fetal Hydantoin Syndrome
Noonan Syndrome	Huntingtons Disease
Turner Syndrome	Intracranial Tumors (Malignancies)
CONGENITAL DISORDER	Neurofibromatosis (Neurocutaneous Disorder)
Cleft Lip	Seizure Disorder
Congenital Adrenal Hyperplasia	Tuberous Sclerosis (Neurocutaneous Disorders)
Dwarfing Syndrome	**SEVERE SENSORY IMPAIRMENT**
Hydranencephaly	Albinism
Hydrocephalus	Amblyopia
Vater Association	Aniridia
INBORN ERROR OF METABOLISM	Cataracts (Congenital)
Galactosemia	Glaucoma
Glycogen Storage Disease (e.g. Pompe's)	Melnick-Fraser Syndrome
Hyperpituitarism	Retinitis Pigmentosa
Hypoadrenocortical Function	Retinopathy of Prematurity (ROP)
Hypopituitarism	Waardenburg Syndrome
Hypothyroidism	**PERINATAL FACTORS**
Phenylketonuria (PKU)	Bronchopulmonary Disease (BPD)
Wilson Disease	Failure to Thrive (FTT)
INFECTIOUS DISEASE	Maternal Factors (PKU, Teratogen Exposure)
Bacterial Meningitis	Observed Infant Behavior State Abnormalities
Congenital Herpes	**CHRONIC MEDICAL ILLNESS**
Cytomegalovirus (CMV)	Cancer (Medical Illness)
Encephalitis	Chronic Hepatitis
Human Immunodeficiency Virus (HIV)	Congenital Heart Disease
Toxoplasmosis	Cystic Fibrosis
Viral Meningitis	Diabetes
TOXIC EXPOSURE	Renal Failure
Maternal Phenylketonuria (PKU)	Sickle Cell Disease
Maternal Substance Abuse	Other Hemoglobinopathy
Mercury Exposure (Postnatal)	Hemophilia
	Alpha Thalassemias
	Beta Thalassemias

2.1.5 Determination That a Child is Not Eligible

If based on an initial or annual evaluation, the multidisciplinary team determines that a child is not eligible, the Interim Service Coordinator (ISC) (in the case of an initial evaluation) or the Ongoing Service Coordinator (OSC) (in the case of an annual evaluation) must provide the parent with prior written notice and include information about the parent's right to dispute the determination through WV Birth to Three dispute resolution procedures as defined in WV Birth to Three Procedural Safeguards.

In addition, the ISC or OSC will assist the parent to complete a referral to Help Me Grow West Virginia developmental screening and information and referral program. The ISC or OSC will also complete with the parent, a Transition Resource page with potential resources to address questions or concerns of the parent.