

Diagnosed Conditions and Atypical Development – Guidance for Wisconsin’s Birth to 3 Program (FINAL DRAFT1/6/04)

Children are found eligible for Wisconsin’s Birth to 3 Program because of:

- a) A diagnosed physical or mental condition with a high probability of resulting in a developmental delay, based on the early intervention team’s informed clinical opinion and supported by a physician’s report documenting the condition.
- b) A developmental delay of 25% (or 1.3 standard deviation below the mean) in one or more areas of development. This delay is documented from a number of perspectives (i.e., observations in natural environments, testing procedures, review of records, parent report and informed clinical opinion) by a qualified early intervention team that includes the parents.
- c) Atypical development that is based on the informed clinical opinion of the early intervention team. When testing results closely approach but do not demonstrate a delay (25% or -1.3 S.D.) and observations indicate that some aspect of the child’s development is atypical and adversely affecting the child’s overall development, the early intervention team may use alternative procedures to document atypical development and conclude that the child should be considered developmentally delayed.

The following information was prepared by the Birth to 3 Eligibility Work Group to give clarity to an evaluation team in determining a child’s eligibility for the Birth to 3 Program in Wisconsin.

A. Diagnosed Conditions:

Some children served by Wisconsin’s Birth to 3 Program are found eligible based on a diagnosed condition that has a high probability of resulting in a developmental delay. High probability implies that a clearly established case has been made for a developmental delay. In Wisconsin, “high probability” is defined as **50% or greater likelihood of delay**.

Information regarding diagnosed conditions changes as medical advances and new information becomes available. For example, it was once believed that all children born with HIV or cocaine exposure would have a high probability of having developmental delays. Recent research and experience has described different outcomes for these children.

Research is a dynamic process and reflects medical and intervention advancements. As a result the eligibility work group has developed a list of diagnosed conditions that is based on the best thinking and research in 2003. The list is based on a) a review of other states’ lists of diagnosed conditions, b) input from physicians with expertise in genetics, neonatology, and development and c) a review of published literature.

See Chart 1 for a listing of the current conditions that conform to the 50% or greater probability guideline. A diagnosis of one of these conditions would mean a child is eligible for Birth to 3 regardless of their current development functioning. Information about the child’s developmental status, however, is needed to develop an Individualized Family Service Plan. This list is **definitive** in that the conditions listed in Chart 1 have a 50% or greater probability of resulting in delay, but it is **not inclusive** as there may be other conditions that will be added.

B. Developmental Delay:

It is not necessary to have a diagnosed condition to be eligible for the Birth to 3 Program. In fact, the majority of children served in Wisconsin’s Birth to 3 Program are eligible because of developmental delays (25% or –1.3 standard deviation below the mean) in at least one of the following five areas of development: cognitive, communication, motor, self-help/adaptive, and social emotional.

Research suggests that there are numerous diagnosed conditions that **do not** have a high probability of resulting in developmental delay. Clearly, there are some diagnosed conditions such as neurofibromatosis and torticollis, for which there is not evidence that a developmental delay will result. This means that these conditions in and of themselves do not point toward eligibility for early intervention; however, there may be other circumstances in the child’s life (e.g., health status, family situations) that may influence the course of the child’s development. When developmental concerns exist concurrent with these diagnosed conditions, the child’s evaluation team would determine eligibility based on whether there is delayed or atypical development. (See Chart 2-I & II.)

C. Atypical Development: In some instances a 25 % delay or a -1.3 SD below the mean may not exist, but in the opinion of the early intervention team, some aspect of the child's development is atypical. The development may be unusual in its pattern and adversely affects the child's overall development. Under these circumstances, the team substantiates their clinical opinion with observations, interpretations of test results, review of records, and parent reports to determine eligibility based on atypical development. Under these circumstances, it is the child's atypical development, not a condition that leads to eligibility. (See Chart 2-III.)

Chart 1: Diagnosed Conditions

Examples of diagnosed conditions with a high probability (50% or more) of resulting in developmental delay are listed below. Please note that this is a definitive, but not an inclusive list.

- 1. Genetic**
 - A. Chromosomal anomalies
(Down syndrome, trisomy 13, trisomy 18, 5p deletion syndrome(Cri du chat), 4p deletion syndrome, Fragile X syndrome-in boys)
 - B. Inborn errors of metabolism
(. Hurler-Scheie syndrome, Untreated or poorly controlled PKU, Maple Syrup Urine disease, Tay-Sachs disease, Lesch-Nyhan disease)
 - C. Other:
(Angelman syndrome, Prader-Willi syndrome, deLange syndrome, Smith-Lemli-Opitz syndrome, Williams syndrome, CHARGE association, Osteogenesis Imperfecta, Achondroplasia)
- 2. Perinatal**
 - A. Extreme prematurity (born at 26 weeks gestation or earlier)
(This is not a standard definition but for use with this document only.)
 - B. Extremely low birth weight (less than 1000 grams or 2.2 pounds)
 - C. Prenatal infections
(Toxoplasmosis, Rubella, CMV, Herpes, TORCH)
 - D. Prenatal toxic exposures
(Fetal alcohol syndrome-FAS)
 - E. Fetal and Neonatal Hemorrhage
(Grade III or Grade IV Intraventricular Hemorrhage)
- 3. Neurological**
 - A. Congenital anomalies of the brain
(holoprosencephaly, lissencephaly, microcephaly)
 - B. Anomalies of the spinal cord
(meningomyelocele)
 - C. Degenerative or progressive disorders
(muscular dystrophies, leukodystrophies, spinocerebellar disorders, pediatric AIDS)
 - D. Cerebral palsy, all types, including generalized hypotonic patterns
 - E. Abnormal movement patterns
(ataxias, myoclonus, dystonia)
 - F. Neurocutaneous diseases (Sturge-Weber, Tuberous sclerosis)
 - G. Other CNS influences -CNS trauma
(shaken baby syndrome or sudden impact syndrome)
- 4. Sensory**
 - A. Blind or visually impaired
 - B. Deaf or hard of hearing as defined by the Wisconsin Birth to 3 Universal Newborn Hearing Work Group, 2001 (See page 5.)
- 5. Physical**
 - A. Congenital
(Arthrogryposis multiplex congenital)
- 6. Social-emotional**
 - A. Autism disorders, pervasive developmental disorder (PDD) as diagnosed by a licensed psychiatrist or clinical psychologist under the classification system in the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood/ American and/or the Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV R)*

Chart 2: Evaluate for Developmental Delay, including Atypical Development

This chart describes the five areas of development considered for determining a developmental delay and lists examples of diagnosed conditions and atypical behaviors that may bring a child to the Birth to 3 Program for consideration of eligibility. Children with these conditions or characteristics **should be screened and/or evaluated** for Birth to 3 eligibility based on concerns regarding their current developmental circumstances.

I. Developmental Delays

To conclude that a child is eligible, the early intervention team must document a 25% delay or development that is 1.3 standard deviation below the mean in one or more of the five developmental areas below.

1. Cognitive development;
2. Physical development, including vision and hearing;
3. Communication development;
4. Social and emotional development; and
5. Adaptive development, including self-help skills

II. Diagnosed Conditions

The following diagnosed conditions **do not have documented evidence** of having a high probability of resulting in developmental delay. However, children with these conditions **may have** developmental delays or atypical behaviors that would result in their eligibility for the Birth to 3 Program. If the child has a condition not listed below in Chart 2 or previously in Chart 1, the early intervention team should investigate the probability of the condition resulting in delay.

1. Genetic (with increased risk for developmental delay)

- A. Chromosomal anomalies
(Turner syndrome, Fragile X syndrome (in girls), 22q deletion syndrome)
- B. Inborn errors of metabolism
(Classical Galactosemia, Homocystinuria)
- C. Other Syndromes
(Goldenhar syndrome, Neurofibromatosis, Marfan syndrome)

2. Perinatal

- A. Premature (born 27 to 37 weeks gestation)
- B. Small for gestational age (SGA) (weighing less than the 10th percentile for gestational age, using a standard weight-for-age chart)
- C. Low birth weight (born 1001 to 2000 grams)
- D. Prenatal toxic exposures
(alcohol, polydrug exposure, fetal hydantoin syndrome, exposure to cocaine, exposure to narcotics)
- E. Fetal and Neonatal Hemorrhage
(Grade I intraventricular hemorrhage)
- F. Other Conditions originating in the perinatal period
(seizures, low apgars)

3. Neurologic

- A. Anomalies of the brain
(absence of the corpus callosum, hydrocephalus, macrocephaly)
- B. Anomalies of the spinal cord
(tethered cord)
- D. Epilepsy
- E. Abnormal movement patterns
(severe tremor, gait problems, asymmetry in movement)
- E. Other CNS influences
 1. CNS or spinal cord tumors
 2. CNS infection (e.g. meningitis, abscess)
 3. CNS toxins (e.g. lead poisoning)
- F. Variant speech and language patterns
(e.g. intelligibility, fluency)

4. Sensory

- A. Low vision after correction
(e.g. severe strabismus, visual field defects, poor functional use of vision)
- B. Intermittent hearing loss
(e.g. chronic otitis media or serous otitis-media greater than 4 months duration)

5. Physical

- A. Congenital
(e.g. cleft lip and palate, torticollis, limb deformity, club feet, hip dysplasia)
- B. Acquired
(e.g. severe arthritis, scoliosis, brachial plexus injury)
- C. Chronic illness or medically fragile
(e.g. delays in a child's development that may result from an illness or treatment for an illness such as chronic heart disease, cystic fibrosis, technology dependent, hypothyroidism, or cancer)

6. Social Emotional

- A. Diagnosed psychiatric conditions or severe emotional/behavioral disorders diagnosed by a licensed psychiatrist or clinical psychologist under the classification system in the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood*/ American and/or the Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-R)
(mood disorders of infancy or early childhood - anxiety, depression, disruptive behavior disorders, reactive attachment disorder of infancy or early childhood, post traumatic stress disorder, self injurious behaviors)

III. Atypical Behavior

The following examples describe circumstances under which a child may demonstrate atypical development that should be considered a developmental delay. When parents and others identify concerns in these areas, and test results approach, but do not demonstrate a delay (25% or -1.3 S.D.), alternative measures including observations and parent reports should be used to make an informed opinion about whether a child should be **considered** developmentally delayed.

1. Growth and Feeding

(e.g. severe growth delay, failure to thrive, feeding problems, gastrostomy for feeding)

2. Sensory and Regulatory

(chronic problems with sleep, attention, and/or eating; sensory processing disorders)

3. Chronic Illness/Medically Fragile

(differences in a child's development that may result from an illness or treatment for an illness such as chronic heart disease, cystic fibrosis, technology dependent, hypothyroidism, cancer)

4. Social Emotional

(atypical social interaction with caregivers and peers, delays or differences in ability to communicate emotional needs or achieve expected emotional milestones such as pleasurable interest in adults and peers)

References: Information from these states' early intervention program guidelines was used to assist in developing guidance for Wisconsin's Birth to 3 Program: Georgia, New Mexico, New York, Rhode Island, Utah, and Virginia.

Wisconsin Birth to 3 Program Determining Eligibility for Children with Hearing Loss

The process for determining eligibility for early intervention is the basis for determining eligibility for children with hearing loss. A child is eligible for early intervention services under the Birth to 3 Program if the evaluation conducted by the early intervention team determines that the child is developmentally delayed or that the child has a diagnosed physical or mental condition which will likely result in developmental delay. A determination of high probability that a child's diagnosed condition will result in a developmental delay must be based upon the team's informed clinical opinion supported by a physician's report documenting the condition. High probability implies that a clearly established case has been made for a developmental delay.

Early intervention team members. Any early intervention team performing an evaluation must include a service coordinator and at least one member who has expertise in the assessment of both typical and atypical development and expertise in child development and program planning. Parents should be involved throughout the evaluation process. Members of the early intervention team must be from two different disciplines in the areas of the child's suspected needs.

Therefore, for a child with a diagnosed hearing loss, one or more members of the early intervention team must be able to interpret audiological reports and understand the developmental impact of hearing loss.

Eligibility for a child with diagnosed hearing loss. The regulations for the Birth to 3 Program do not base eligibility on specific types or degree of hearing loss. There is no required decibel loss nor are children with unilateral hearing loss excluded.

Once a child with a diagnosed hearing loss is referred, the early intervention team needs to determine whether the child's hearing loss is likely to result in a developmental delay. The team needs to consider factors such as the type and degree of the hearing loss, the presence of other conditions, and the potential effects of the hearing loss on the development of the child. The team should make use of the scientific evidence about the long-term developmental consequences of hearing loss in infants and toddlers. A child with a hearing loss does not need to demonstrate a developmental delay to be eligible for the Birth to 3 Program.

If the early intervention team determines that the child's hearing loss is not predicted to result in developmental delay, they must offer to reconsider the child's eligibility within 6 months. The early intervention team should also provide information about, and offer to refer the family to, community services that may benefit the child and family.

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