Diagnosed Conditions and Atypical Development Guidance for Wisconsin's Birth to 3 Program

Children may be found eligible for Wisconsin's Birth to 3 Program because of:

- 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.
- A developmental delay of 25 percent (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 such as 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.
- 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 percent or -1.3 standard deviation) 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 whether the child should be considered developmentally delayed.

Diagnosed Conditions

Some children receiving services from the Wisconsin 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 percent (*50%) or greater likelihood of delay.*

Information regarding specific diagnosed conditions changes as medical advances and new information becomes available. For example, it was once believed that all children born with Human Immunodeficiency Virus (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 which reflects medical and intervention advancements. As a result, the list of diagnosed conditions is based on the best thinking and research in 2014. The list is based on:

- A review of other states' lists of diagnosed conditions.
- Input from physicians with expertise in genetics, neonatology, and development.
- A review by the Wisconsin Chapter-American Academy of Pediatrics.

- A review of published literature.

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

When a condition presents itself that is not on Chart 1, the county Birth to 3 Program may need to determine as a team whether or not the condition has a 50 percent or greater probability of resulting in a developmental delay. First, the program would review the list of diagnoses in Chart 2 which do NOT result in a 50 percent or greater probability of resulting in a developmental delay. If the condition is not listed on Chart 2, the program would research the condition through one or more means, including but not limited to:

- Completing a web-based search.
- Talking with a geneticist.
- Contacting organizations such as the National Organization of Rare Disorders (NORD).

The county Birth to 3 Program would meet as a team and use their professional opinion and discretion to make a team decision of whether or not the condition meets the 50 percent or greater probability guideline. If the 50 percent or greater probability guideline is met, then the child would be eligible for the Birth to 3 Program due to diagnosis. If it is not, further evaluation would be required to determine a 25 percent delay in one or more areas of development.

Chart 1: Diagnosed Conditions

Examples of diagnosed conditions with a high probability (50 percent or more) of resulting in developmental delay are listed below. Children with these diagnoses are eligible for the Birth to 3 Program based upon this diagnosis. **Please note that this is a definitive, but not an inclusive, list.**

Genetic	Chromosomal anomalies	• Cri-du-chat syndrome [5p deletion] • DiGeorge syndrome [22q11 deletion] • Down syndrome [Trisomy 21] • Edwards syndrome [Trisomy 18] • Fragile X syndrome in boys • Patau syndrome [Trisomy 13] • Wolf-Hirschhorn syndrome [4p deletion syndrome]
	Inborn errors of metabolism	• Galactosemia • Hunter syndrome (Mucopolysaccharidosis type II) • Untreated Hypothyroidism • Lesch-Nyhan syndrome • Maple Syrup Urine disease

		• Mucolipidosis (type II, III) • Peroxisomal disorders • Untreated or poorly controlled Phenylketonuria (PKU) • Storage disorders [such as Hurler syndrome (Mucopolysaccharidosis type I)] • Tay-Sachs disease • Untreated Wilson syndrome
	Other	• Achondroplasia • Angelman syndrome • Cornelia de Lange syndrome • CHARGE syndrome • Kabuki Syndrome • Noonan syndrome • Osteogenesis Imperfecta • Prader-Willi syndrome • Rett syndrome • Rubenstein-Taybi syndrome • Russell-Silver syndrome • Smith-Lemli-Opitz syndrome • Smith-Madenis • Treacher Collins syndrome • Williams syndrome
Perinatal	Extreme prematurity (less than 32 weeks) (This is not a standard definition but for use with this document only.)	
	Very low birth weight (less than 1500 g or 3.31 lbs)	
	Prenatal infection	• Cytomegalovirus (CMV) • Herpes simplex • Rubella (congenital) • Syphilis (congenital) • TORCH-Toxoplasmosis
	Prenatal toxic exposures: Fetal alcohol spectrum disorders	
	Fetal and Neonatal Hemorrhage: Grade III or Grade IV Intraventricular Hemorrhage	
	Other	• Cyanotic Heart Disease • History of extracorporeal membrane oxygenation (ECMO) • Lead toxicity (greater than 10 mcg/dL) • Small for gestational age (SGA)
Neurological	Congenital anomalies of the brain	• Encephalopathy • Hemimeagalencephaly • Holoprosencephaly spectrum • Microcephaly • Miller-Dieker syndrome [17p13.3 deletion syndrome or lissencephaly] • Semilobar holoprosencephaly

	Anomalies of the spinal cord	• Meningomyelocele • Myelomeningocele • Spina bifida
	Degenerative or progressive disorders	• Leukodystrophy • Muscular dystrophy • Pediatric AIDS • Spinocerebellar disorders
	Cerebral palsy, all types, including generalized hypotonic patterns	
	Abnormal movement patterns	• Ataxia • Dystonia • Myoclonus • Opsoclonus Myoclonus syndrome
	Neurocutaneous diseases	• Sturge-Weber • Tuberous sclerosis complex
	Central nervous system (CNS) influences – hypertonia	
	CNS trauma	• Shaken baby syndrome • Spinal cord injuries • Sudden impact syndrome
	Other	• Hydrocephalus • Hypotonia • Hypoxic-ischemic encephalopathy • Infantile spasms • Myastenia (congenital) • Neonatal seizures • Seizure disorders in newborn period (not febrile) • Stroke • Traumatic brain injury (admission Glasgow Coma Scale (GCS)<8) • West syndrome
Sensory	Blind or visually impaired, persistent hyperplastic primary vitreous	
	Hearing impairment, Waardenburg syndrome (with hearing loss)	
	Deaf-blind	
Physical	Craniofacial: cleft palate with or without cleft lip	
	Other	• Arthrogryposis multiplex congenital • Phocomelia
Social-Emotional	Autism disorder or pervasive developmental disorder (PDD)	
	Anxiety disorder of infancy and early childhood	
	Depression of infancy and early childhood	
	Disinhibited social engagement disorder	
	Post-traumatic stress disorder (PTSD)	
	Reactive attachment disorder	
Medically Complex	History of cardiac arrest	
	Congenital heart disease (requiring surgical repair)	
	Tetralogy of fallot	
Growth and Feeding	Failure to thrive	
	Feeding tube, g-tube, ng-tube	

Technology Dependent	Tracheostomy
	Ventilator dependent

Developmental Delay

It is not necessary for a child 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 percent or –1.3 standard deviations below the mean) in at least one of the following five areas of development: 1) cognitive, 2) communication, 3) motor, 4) self-help/adaptive, and 5) social emotional.

Many children have a diagnosed condition that **does not** have a high probability of resulting in developmental delay (See Chart 2). For example, neurofibromatosis and torticollis are diagnosed conditions for which there is no evidence that a developmental delay will result. This means that these conditions, in and of themselves, do not result in eligibility for early intervention.

Chart 2: 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. Children with these conditions or characteristics should be screened and/or evaluated for Birth to 3 Program eligibility based on concerns regarding their current developmental circumstances. Please note that this is a definitive, but not inclusive list.

Genetic	Chromosomal anomalies	• 22q deletion syndrome • Fragile X syndrome (in girls) • Turner syndrome
	Inborn errors of metabolism	• Classical • Homocystinuria
	Other syndromes	• Goldenhar syndrome • Marfan syndrome • Neurofibromatosis
Perinatal	Prenatal toxic exposures	• Alcohol • Exposure to cocaine • Exposure to narcotics • Fetal hydantoin syndrome • Polydrug exposure • Neonatal Abstinence syndrome
	Fetal and neonatal hemorrhage: Grade I intraventricular hemorrhage	
	Other conditions originating in the perinatal period	• Low Apgar • Seizures (febrile)
Neurological	Anomalies of the brain	• Absence of the corpus callosum • Macrocephaly
	Anomalies of the spinal cord: tethered cord	

	Epilepsy	
	Abnormal movement patterns	• Asymmetry in movement • Gait problems • Severe tremor
	Other central nervous system (CNS) influences	• CNS infection (e.g., meningitis, abscess) • CNS or spinal cord tumors • CNS toxins (e.g., lead poisoning)
	Variant speech and language patterns	• Fluency • Intelligibility
Sensory	Low vision after correction	• Poor functional use of vision • Severe strabismus • Visual field defects
	Intermittent hearing loss: chronic otitis media or serous otitis media greater than 4 months duration	
Physical	Congenital	• Cleft lip • Club feet • Hip dysplasia • Limb deformity • Torticollis
	Acquired	• Brachial plexus injury • Scoliosis • Severe arthritis
	Chronic illness or medically fragile	• Cancer • Chronic heart disease • Cystic fibrosis • Hypothyroidism (treated) • Technology dependent
Social-Emotional	Mood disorders of infancy or early childhood	
	Disruptive behavior disorders	
	Self-injurious behaviors	

Atypical Development

In some instances, a 25 percent (25%) delay or a -1.3 standard deviation below the mean may not exist, but the informed clinical opinion of the early intervention team is that some aspect of the child's development is atypical. The development may be unusual in its pattern and therefore it adversely affects the child's overall development. Under these circumstances, the team uses alternative procedures or instruments that meet acceptable professional standards to document the atypical development and to conclude, based upon informed clinical opinion, that the child should be considered developmentally delayed based on atypical development. Under these circumstances, it is the child's atypical development, not a diagnosed condition that leads to eligibility. (See Chart 3.)

Chart 3 describes circumstances under which a child may demonstrate atypical development. Alternative measures need to be used to make an informed decision about whether the atypical

development of the child is **considered** developmentally delayed and therefore eligible for the Birth to 3 Program.

Chart 3

Growth and Feeding	• Failure to thrive • Feeding problems • Gastrostomy for feeding • Severe growth delay
Sensory and Regulatory	• Chronic problems with sleep, attention, and/or eating • Sensory processing disorders
Chronic Illness/Medically Fragile	• Cancer • Chronic heart disease • Cystic fibrosis • Hypothyroidism • Technology dependent
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
Motor	• Asymmetrical movements • Atypical tone • Poor balance • Problems in motor planning
Communication	Variant speech and language pattern