# Infant Toddler Development Training
# Module 6

**Module Description**

This module provides information about pediatric health issues which influence infants and toddlers with medically complex or low incidence disabilities. It addresses the effect of health issues on the development of infants and toddlers with special needs. The themes of the module include types of health issues and diseases, public health concerns related to infants and toddlers, assessment of medical information for scientific validity, and the effect of a child's condition on the family and community. In depth discussion is provided on sensory impairments, orthopedic conditions, autism spectrum disorders, and neurological impairments as well as numerous other medically complex conditions and low incidence disabilities.

**Required Readings**

The required text for this module is: Sandall, S., McLean, M. E., Smith, B.J. (Eds.) (2000). DEC Recommended Practices in Early Intervention/Early Childhood Special Education. Denver, CO: Division of Early Childhood. Learners will also need to access the Resource Bank for Adobe Acrobat (PDF) documents and website material. Learners should be aware that links to websites and additional articles are likely included within the various lessons of this module. Participants are expected to carefully read assigned materials and be prepared to answer questions regarding all content during the self- assessments and final evaluation.

**Module Objectives and Corresponding Florida Department of Health (FDOH) Competencies**

1. Review medical conditions/concerns that affect normal development or place a child at risk for disability or delay including abuse/neglect, biological factors, premature birth, birth trauma, environmental/cultural factors, and attachment/emotional factors (FDOH B3).
2. Compare and contrast differences in newborn development related to health status and medical treatment (FDOH B5).
3. Review awareness of the critical development that occurs during the prenatal period to three years of age. (FDOH B1)
4. Identify appropriate basic health, safety, nutrition, immunizations, and sleep appraisals and programs available for infants and toddlers. (FDOH C7).
5. Demonstrate an understanding of and adherence to requirements for appropriate first aid, CPR, emergency care of seizures and child abuse reporting (FDOH B14).
6. Demonstrate knowledge of types of developmental disabilities and other disorders, (i.e., sensory impairments, chronic illness, genetic syndromes, and cognitive delays), their causes, signs, symptoms, and effect on the child and family (FDOH B4).
7. Analyze legal and ethical issues related to the provision of care for infants and toddlers who are medically complex and/or developmentally delayed (FDOH A2 – 12, H2).
8. Describe frequently used medications and adaptive equipment for children with special needs FDOH B8).
9. Use diagnostic reasoning to fully participate in the development of an Individualized Family Support Plan and Plan of Care that is individualized to meet a child's fluctuating nutrition, health, or medical status within the context of family needs, priorities, and activities (FDOH F2, F5).
10. Demonstrate an understanding of infants and/or toddlers who are technology dependent (i.e., those with gastrostomy and tracheostomy tubes) (FDOH G 11).
11. Demonstrate knowledge of the affect a child with a medically complex condition or low incidence disability has on a family and how the impact on the family affects the child (FDOH B12 – 13).

12. Identify appropriate and valid national and community resources to substantiate information or services to meet the medical and developmental needs of infants and toddlers who are medically compromised. (FDOH F4).

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**Introduction**

This lesson presents basic knowledge related to health and disease in infants and toddlers. The information will assist the Infant Toddler Developmental Specialist (ITDS) in determining appropriate developmental interventions for infants and toddlers with special needs. Issues related to the health of the newborn are addressed with special emphasis on the medical and health concerns of the premature infant. Health issues related to developmental disabilities in general are summarized. A broad overview of the funding of health care services for infants and toddlers and an introduction to medical ethics is provided.

**Learning Objectives**

Upon completion of this lesson, you will be able to:

1. Define health and disease.
2. Cite the elements of valid medical literature.
3. Explain the basics of newborn development and care.
4. Discuss the issues related to the health of premature infants.
5. Demonstrate an understanding of the health issues related to infants and toddlers with developmental disabilities.
6. Cite the causes, incidence and prevalence of infant morbidity and mortality.
7. Demonstrate knowledge of the effect that a child with a medically complex condition and/or intensive special need has on a family and how the child is affected within the family dynamics.
8. Describe funding sources to assist families with the health care needs of infants and toddlers.
9. List the ethical considerations in the provision of health care for infants and toddlers with medically complex conditions and/or intensive special needs.

**Resources**

The following resources are necessary for the completion of this lesson. Learners may wish to access and print a hard copy of the resources prior to beginning the lesson and for future reference. Some resource documents can be found in the Resource Bank. Others are available online.

As you look at infant data for Florida on the websites, print the neonatal birth and death rates for Florida. Be prepared to answer questions on the categorical breakdown of information that is provided relating to infant birth and death rates.

- Department of Health
- Florida Department of Health Vital Statistics

**Key Words**

Definitions of key words are found in the glossary.

- Anomaly
- Asphyxia
- Bacterial sepsis
- Biotinidase deficiency
- Corpus callosum
- Cystic fibrosis
- Duodenal atresia

- Esophagitis
- Gastroschisis
- Hypoperfusion
- Hypoxia
- Immunoglobulins
- Imperforate anus
- Intracranial Hemorrhage
- Intrauterine Growth Retardation
- Phenylketonuria
- Projectile Vomiting
- Pyloric Stenosis
- Spina Bifida
- Tracheal-Esophageal (T-E) Fistula

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**Reading Medical Literature for Validity**

The ability to read medically related information for accuracy and validity is a basic requirement for the ITDS working with all children and families, especially those with medically complex conditions and/or intensive special needs. It is important for the ITDS to know how to read and assess the validity of health and disease information to better understand the strengths and limitations of children. Access to valid medical information will help the ITDS to create developmental strategies that support infants and toddlers with chronic and complex health conditions. The ITDS also needs access to information related to acute illnesses experienced by infants and toddlers, including those who have developmental disabilities or delays. This will help the ITDS to understand, plan and carry out or implement appropriate interventions in relation to the health of the child within the dynamics of the family.

When reading research articles there are guidelines to consider when determining whether the information represents an issue that has been adequately explored or has evidence-based studies to back up its claim. Guidelines that are followed by Clinical Evidence can assist you in reading the medical literature. Some of the main points to consider are:

- information presented has an extensive literature review
- material has been subjected to a stringent supervised peer review process
- mechanism for feedback and correction is provided
- clear hypothesis and research design to determine the validity of the hypothesis is presented.

**What is Health?**

As you begin your study of pediatric health issues related to infants and toddlers with complex medical conditions or low incidence disabilities, it is important to remember why we must be vested in the health of children. Children represent the future of a society. We advocate for children and strive to enhance the environments where they live because they do not have a legal voice of their own. Therefore, it becomes the role of members of a society to nurture and protect its children.

Children are not miniature adults. They have unique characteristics; one of which is their complete dependence on their caregivers when very young. Human children require more time to become competent in assuming an adult role than any other species. The complexity of their development and the need to nurture that development makes humans

unique. The continuity of children's health and wellness should be protected in order that society can benefit, and children and families can live healthy and productive lives.

What are the characteristics of health?

What does health mean for the person who has a chronic health condition?

**Public Health, Health Care and Health Care Professionals**
Public health is the art and science that deals with the protection and improvement of health through an organized community effort. Public health includes preventive medicine, sanitary and social science. Health care and the financing of health care are elements of both individual health as well as public health.

Health care is the maintenance and restoration of balance within the health continuum by the prevention and treatment of disease, often by specially trained and licensed professionals from a variety of fields. Health care professionals play a key role in maintaining and restoring health. However, they are not the only individuals in a society that provide health care. For example, the childcare worker may not typically be thought of as a health care provider, yet they provide for the care and wellbeing of young children in our society daily. Still, most members of our society consider medical professionals as the first or primary level of health care providers.

The building and maintenance of a positive relationship among health care professionals such as a physician, nurse, and a therapist develop and is maintained over time. The family usually chooses the role a health care professional has in their child's life. In particular, the child's primary medical physician often plays the role of a gatekeeper by assisting the family with apportioning care and roles. Regardless of the primary source of health care, it is imperative that infants and toddlers have a medical home (primary care physician) for continuity of care. A medical home serves as the hub and source of consistent medical care, record keeping, and intervention supports and services.

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**What is Disease?**
Disease is precise and involves pathological information that can be communicated to another individual so that a course of treatment can be planned, and the results of the treatment can be determined. The causes of disease include environmental elements, infection and defects that may be inherent in the individual. Disease can be acute or chronic. Acute disease generally has a more rapid onset, and the duration of the disease is for a shorter period. A chronic disease or condition is one that is recurrent and lasts a lifetime.

A disease or health condition is one that is manifested by symptoms and positive laboratory results or other medical diagnostics. The condition may be present long before the signs (objective physical evidence) and symptoms (subjective complaints) of the disease are manifested. If a person is diagnosed with a chronic disease, it remains a condition of the person for life. In general terms, the disease cannot be cured by medical treatment although the external signs and more pronounced symptoms can be treated or ameliorated. A key characteristic of disease is the presence of a disability represented by loss or absence of function due to sequelae (aftermath associated with the disease).

Disease is an unhealthy condition of the mind and body. It can suggest either a physical or a social state. It includes both the physical well-being of an individual as well as the state of mind and may encompass the cultural beliefs of the individual.

**Aspects of Chronic Disease in Children**
One or more of the following are present in chronic disease for a child:

1. Limitations of functions appropriate for age or development
2. Disfigurement
3. Dependency on medication or special diet for normal functioning or control of condition
4. Dependency on medical technology for functioning
5. Need for more medical care or related services than usual for the child's age
6. Special ongoing treatments at home or in school

Generally, chronic diseases in children are relatively rare given the entire population of children. They are not particularly stable, often leading to periods of worsening and remission. This episodic nature is overlapped onto the development of the child and can affect the child's functioning in all domains.

**Incidence and Prevalence of Chronic Health Conditions**
Overall incidence (number of cases) of rare health conditions has not changed much over time. However, because of the advances in medical care and improvements in technology, children who would have died (mortality) at an early age are surviving and there is an increased prevalence of morbidity (effects of the condition) in the survivors. Therefore, the percentage of chronic conditions in the pediatric population is increasing. Facts relating to the declines in mortality include:

- advances in technology
- improved treatment of infectious diseases
- improved diagnoses and case finding of children with unrecognized conditions, and implementation of public and preventive health measures.

While thirty-one percent (31%) of all children have some sort of chronic health condition, two-thirds of these do not have significant functional limitation. Only, about ten percent (10%) have varying amounts of disability. Reduction of functional impairment is a goal of intervention and treatment.

**Improvement in Infant Mortality Results in Increased Morbidity**

Although progress has been made in reducing infant death (mortality), increased morbidity or effects associated with the conditions that require medical or surgical intervention has been the result. Listed below are some examples of conditions where medical science has made progress in increasing life expectancy and where this has resulted in increased morbidity that must be addressed by the medical team:

- Cystic fibrosis data and follow-up shows more children are surviving into adulthood with improved technology and medications
- Spina bifida data and follow-up shows improved life expectancy with better surgical interventions and improved control of urinary tract infections
- Phenylketonuria data and follow-up shows that many children with this error of metabolism have benefited due to the detection of the disorder with newborn screening programs and early dietary interventions. This intervention has drastically reduced the number of individuals with this condition who have mental retardation or autism and the life expectancy for the individuals has improved so that they survive to adulthood. These children must be managed in the prenatal and post- natal periods to reduce disabilities.
- The survival rate for children with traumatic injuries has improved; however, this has created an increase in numbers of children with more debilitating disabilities.

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**History of Health Care Barriers**

As explained earlier, advances in technology have improved various rates of morbidity and mortality. Prior to 1930, antibiotics were not available. Therefore, respiratory, and other infectious diseases caused significant mortality in the entire population, especially in young children. As antibiotics were introduced, decreases in infectious deaths allowed some children to survive, but with residual problems. Technological gains in the 1960's and 1970's have resulted in intensive care measures allowing more premature infants to survive at earlier gestational ages. However, financing these advances and the subsequent costs of an increased number of surviving infants with disabilities and medical problems has underscored society's responsibility for allocating these resources and apportioning care for children, as well as other populations.

Overarching barriers to health care include poverty, ethnicity, and language differences. Lack of insurance and the high cost of health and medical care are the largest barriers. Other barriers include fragmented care when there is no coordination with a primary pediatrician or primary specialist who can oversee a complex condition that requires intensive management. Practitioners also have difficulty staying abreast of changes in the field. These barriers reduce their ability to deliver optimal care to children with complex medical conditions.

The emergence and practice of managed care networks sometimes works against a family who is seeking care for their child with a complex medical condition or chronic disease. The family and the primary physician must justify expenses for necessary care. The managed care systems work much better for healthy populations.

The American Academy of Pediatrics recommends that the physician maintain a central data base with pertinent diagnostic and consultative information in caring for children with disabilities and their families and help provide ongoing services designed to prevent secondary disabilities. It is believed that the delivery of quality care is more effective when a child with a chronic disease has a medical home with a primary physician who can act as a translator for health care systems and can advocate for their individual needs rather than having health care that is episodic in nature.

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**Development**

Development is predictable and is seen as the outward expression of the maturing nervous system. Normal development is constant in rate and sequence and is assisted through interaction with caregivers.

Newborns are initially assessed in the immediate neonatal period to determine their health status. Dr. Virginia Apgar developed the Apgar Scale in the early 1950's. There are five components to score, and each component is scored between 0 and 2 with a total possible score of 10. The score is determined by the following five factors:

1. heart rate
2. respiratory rate
3. muscle tone
4. reflex irritability
5. color

These are shown on the Apgar rating system

A newborn baby is a highly complex individual who is completely dependent on another person, usually the mother, for its care and nurturance. At birth, the newborn already has a remarkable capacity to interact. Social interaction with their caregivers supports the development of the infant. It is now recognized that the development of social competencies, in infancy, influences later cognitive functioning. This need of social interaction could be seen as a biological drive. This is important for the Infant Toddler Developmental Specialist (ITDS) to remember when planning interventions with families who have newborns. The affection of caregivers provides a motivation for children to be more compliant possibly because of the social attention they are receiving. For an infant this interaction was once thought to be passive but is now believed to be active. As parents focus attention on their infant and the baby responds, the baby becomes more curious and interactive. The process of interaction becomes increasingly more complex as the infant grows.

Sparrow (2004) states that one of the "touch points" of emotional development is mutual regulation and normal interactions between infants or young children and caregivers. This

involves a process whereby the adult attends to a child's cues and lets the child lead the interactions.

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**Newborn and Infant Development**

This section provides a brief review of newborn development. For more information on developmental domains (streams) please refer to Module 1 of the ITDS series.

There are several conceptualized domains (streams) of development: cognitive, motor, self-help or adaptive, communication and social-emotional. All domains interact and a problem in one area influences the development in another area. As an example, a child with Down syndrome could have delays in cognition that may also be manifested in difficulties related to self-help tasks. There may also be issues with communication because of the delay in cognitive skills. This will also impact the child's attainment of social milestones. In addition, deficits in hearing and vision can further delay development if left untreated.

**Skill Areas**

**Motor:** Motor skills are largely reflexive at birth. The presence of primitive reflexes (involuntary movements that are governed by the brain stem), indicate an intact neurological system. Reflexes are integrated to become protective responses as the infant matures. The maturing infant also demonstrates more consistent voluntary control of their movements, and their primitive reflexes are usually integrated by around six (6) months of age.

**Social:** Most newborns have social skills that show the ability to sustain attention. However, there are innate differences in temperament of the newborn that affects the infant's ability to maintain attention.

**Self-Help:** Initially, the newborn is completely dependent on its caregivers for survival and support. The development of personal/self-help skills begins with the ability to organize sleep and eating patterns. This is followed by an increasing complexity of eating skills, dressing skills, and other more complex self-help behaviors during later stages of development.

**Cognition:** A newborn's cognitive skills are also initially reflexive and are limited because voluntary motor control does not allow for the demonstration of problem solving. The main skills present at this time are manifested in visual attention and eye movements. Newborns learn first to recognize their mother's voice and then other caregivers. They begin to develop more control of their facial muscles including the control of eye movements and they learn to smile in a social manner. The ITDS can alert the parent to recognize the "quiet alert" state of an infant and to use these times to encourage interactions that support this developmental stage.

**Communication:** The newborn's language is primitive, but it is reciprocal in response to an adult caregiver. It can include reciprocal patterns of grimaces and sounds.

**Sensory Areas:** Sensory capabilities at birth show that newborns are legally blind. They can usually only see one to two feet or the distance from their mother's face to her breast or arms. Visual acuity is estimated to be in a range of 20/800 to 20/150. The newborn seems to discriminate colors and shows a preference for patterns.

Hearing in typically developing infants is present, but the response to sounds is not localized. They will become quiet and more alert when spoken to in a soft voice. There will be changes in their heart and respiratory rates if the environment is noisy and chaotic. Some infants are so sensitive to loud or aversive noises that they become easily disorganized and begin crying.

Taste and smell are felt to arise from smelling and tasting the amniotic fluid, however, these capabilities are harder to assess.

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**Health Priorities for the Newborn**
There are four main priorities in the newborn and infancy period.

**First** is the establishment of a reliable source of good nutrition. This may be accomplished by breast-feeding which is considered the preferred method when a mother is able to successfully provide this method of nourishment. Another method is bottle-feeding with a formula that simulates the nutrients found in breast milk.
**Second** is protection from infectious diseases. Well-childcare and routine visits to the primary pediatrician or health practitioner is a must. Infant care includes standard infection control, good hygiene, and vaccinations at specified times.
Well childcare begins with the first examination at birth and a period of observation. The newborn is examined to determine the presence of congenital anomalies and conditions. However, it should be noted that some of these are not determined until a much later age.

Additionally, metabolic screening is considered a part of well childcare. It is provided throughout the United States, but each state specifies which tests are included in their screening process. In Florida, a universal newborn hearing screening program is in place so that sequelae related to hearing loss can be minimized. Vision screens are conducted as part of the routine medical examination. If the need is indicated, more in-depth vision tests are performed for premature infants to rule out retinopathy of prematurity and its sequelae.

Some of the metabolic conditions that are included in Florida's newborn screening program are phenylketonuria (PKU), hypothyroidism, biotinidase deficiency, sickle cell disease, and cystic fibrosis. What other tests are included in Florida's newborn screening program?

**Third**, is the establishment of a nurturing environment. This is essential to the bonding and attachment process and the development of trust. The development of trust is vital to the emotional, as well as physical, well-being of the infant during the first year of life.
**Fourth**, are other health measures to reduce morbidity and mortality. This could include immunizations, hearing testing following failure of newborn hearing screening, reduction of trauma, use of car seats, instructions for parents regarding putting infants to sleep on their backs, and the prevention of shaken baby syndrome.
Putting babies to sleep on their backs has been found to reduce the incidence of Sudden Infant Death Syndrome (SIDS). Information on SIDS can be found through the SIDS Organization and the SIDS Alliance and the National SIDS Infant Death Resource Center provides information to families and professionals who serve families that are dealing with SIDS. Information is available at the SIDS Center

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**Feeding and Related Issues**
Breastfeeding has significant health benefits that make it superior to formula feeding for many infants. Please refer to the AAP Policy on Breastfeeding.
The composition of breast milk is the model for infant formulas. It is lower in protein compared to cow's milk, but higher in carbohydrate and fat. Breast milk contains good cholesterol that is necessary for brain growth. Breast milk is lower in iron, but the iron that is present is bound to a transport protein that is easily digested by the baby. In addition to

providing the nutrients that help the baby to grow, breast milk contains immunoglobulins and t cells that confer a protective immunity to the infant. This helps the infant ward off infections, particularly those related to gastrointestinal infections.

If the breastfeeding experience is successful, it can promote maternal and infant bonding and if it is not, it can become a source of stress and embarrassment to the mother. Pain relief and relaxation are important considerations to success. Sometimes an effective intervention is arranging for a breastfeeding coach through the La Leche League.
It is typical to have occasional spit ups especially with formula feeding because the volumes consumed are usually greater and stay in the stomach longer than breast milk. The segment of the esophagus, at the juncture of the stomach and esophagus acts like a valve. If the segment is relatively lax, there can be a lot of spitting up and this is called gastro-esophageal reflux (GER). Reflux is usually not present at birth, but gradually becomes apparent and worsens with increasing volumes of milk/formula ingested in the first month of life. The reflux is usually not forceful as it is in another condition, that of pyloric stenosis which can result in projectile vomiting and requires surgical intervention. Routine reflux usually improves by six (6) months of age and disappears by one (1) year of age. If there are frequent and severe episodes, one might observe apnea (short period of not breathing), wheezing or choking. One might also observe pain from the esophagitis, and fussiness from the same or from hunger and failure to gain weight. These situations require prompt attention especially if the child is showing a failure to grow.

It is important for the ITDS to recognize that there is a difference between routine regurgitation (spitting up) and vomiting. How would the ITDS differentiate between the two?

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**Problems Arising in Embryonic and Fetal Development**

Problems with development often have their origin in the developing embryo and fetus and often the embryo or fetus self-aborts due to a defect. However, there are survivals through the embryonic stage of 5 -10 weeks when most organ systems are developing and these surviving embryos and then fetuses are born with malformations such as cardiac lesions.

There are fetal conditions that affect subsequent growth. Some of these conditions include infants who:

- are small for gestational age or low birth weight
- have genetic conditions with growth problems as a characteristic of a syndrome
- have infections from teratogens, foreign substances that can cause malformations in the developing embryo or fetus or can affect growth and development

As discussed in Module 1 of the ITDS series, risk factors during pregnancy can affect the outcome of an infant. During pregnancy, the placenta functions as the primary funnel of nutrients to the fetus. Nutrients actively pass from mother to fetus as the metabolic system of the mother regulates the nutrition for the fetus. Thus, a mother's nutritional status is very important to the health and well-being of the baby. The growth issues become more obvious as the fetus grows.

Toxemia or pre-eclampsia and pregnancy induced hypertension can produce vascular changes in the placenta which can result in starving the fetus of adequate nutrients and can produce a newborn that is small for gestational age (SGA). Babies who are small for gestational age are at risk for growth, developmental, and behavioral problems. They are more at risk than infants who are appropriate for gestational age (AGA) to develop hypertension and diabetes as adults.

**Influence of Teratogens**
The Central Nervous System (CNS) is very susceptible to influences of teratogens such as alcohol, drugs, or environmental pesticides, etc. because the CNS takes much longer than most organs to develop. A teratogen may also be a medication or prescription drug taken by the mother during her pregnancy, especially in the first trimester. Also, infections in the mother can pass to the developing fetus and cause problems. These include such things as rubella (German measles), rubeola (measles), varicella (chicken pox), toxoplasmosis, herpes simplex, cytomegalovirus (CMV), syphilis and human immunodeficiency virus (HIV).

**Amniotic Fluid Implications**
Another factor that can influence the outcome for the infant includes the amount of amniotic fluid. Too much fluid (hydramnios or polyhydramnios) may be an indicator for problems such as neuromuscular diseases or obstruction of the gastrointestinal tract. Examples of the latter include imperforate anus, duodenal atresia, gastroschisis, omphalocele, or tracheo-esophageal fistula. Too little fluid (oligohydramnios) may also indicate the presence of problems for the growing fetus. This can be associated with an obstruction of the urinary tract, renal agenesis, immature lung development, and intrauterine growth retardation (IUGR).

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**Premature Infants**
Premature infants contribute significantly to the morbidity and mortality rates discussed earlier in this lesson. Additionally, premature infants and the role of the ITDS were introduced in Module 1 of the ITDS series. The ITDS may be on the team for families who have premature infants. It is important that the ITDS understand terminology related to prematurity when reading reports or participating in team discussions.

In review, the preterm or premature infant is an infant who is born before the 37th week of gestation usually weighing less than 2,500 grams (5 ½ pounds). If an infant is born at 37 weeks or more and weighs less than the 2,500 grams, the infant is said to be small for gestational age. In addition, any infant with birth weight less than 2,500 grams, no matter what the gestational age, is considered low birth weight.

Technology such as incubators, mechanical ventilators, advanced laboratory procedures, antibiotics, and surfactant (to help the premature infant's lungs work better) make it possible to save smaller babies born at younger gestational ages. However, with more infants surviving, the issues of morbidity or the problems related to prematurity have increased.

**Neurological Correction for Premature Infants**
The ITDS must be aware of a very important concept when working with premature babies especially up to the age of two years. This is the concept of neurological correction. The age of the child until the chronological age of two years is adjusted to represent the time that

would have been spent in utero rather than the actual age of the child. This is referred to as the *adjusted age*.
The concept of neurological correction is an important consideration when assessing the development of a premature infant. Professionals who administer developmental tests need to calculate the chronological, as well as the adjusted age, for a premature infant until the infant is two years of age. This adjusted age should be used when calculating the scores on most developmental evaluation/assessment protocols.

Why is it important to understand adjusted age?

A general rule of thumb is that most premature infants are kept in the hospital until they reach a weight of about five pounds or until they reach the term age when they would have been delivered. This is of course providing that the presence of a severe medical condition does not delay the transition to the home.

What family stressors should the ITDS be aware of that are inherent in the NICU experience?

An excellent resource on Premature Infants is available to help the ITDS gain insight on how families feel about and cope with the NICU experience and the transition home. This material was created specifically for parents of premature infants and healthcare providers.

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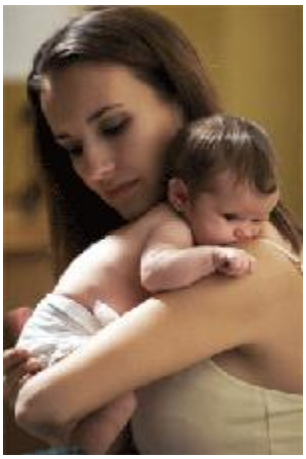
**Premature Infant Appearance**
Premature infants look different than term infants. Generally, most premature infants appear floppy or have lower tone even when they have brain injury that may increase their risk for cerebral palsy and hypertonicity at a later age. Premature infants generally have increased joint mobility as well as low muscle tone. Both factors improve with more advanced gestational age. Other characteristics of the newly born premature infant include:

- the premature infant will lie in an extended position whereas the term infant will lie in a semi-flexed position.
- premature infants have more fine body hair called lanugo.
- their skin is smooth with an absence of creases.
- their ear cartilage and breast tissue are not well developed when compared to a term infant.
- premature infants appear passive, and do not have good behavioral state control and are easily overstressed by aversive stimuli because of the immaturity of their nervous system.

**Other Health Issues Related to Prematurity**



Other health issues of prematurity include a decreased production of surfactant, immature nervous system, inadequate kidney function, immature gastrointestinal tract, immunologic problems, osteopenia of prematurity, and ophthalmologic problems. The decreased surfactant can lead to respiratory distress syndrome (RDS). The immature nervous system puts the infant at risk for:

- intra-ventricular hemorrhage (IVH),
- periventricular leukomalacia (PVL), and
- hydrocephalus.

Inadequate kidney function may lead to acidosis and poor weight gain. Problems of the gastrointestinal system may result in feeding intolerance, necrotizing enterocolitis (NEC), and gastroesophageal reflux (GER), which may persist after the infant is discharged home. The signs of GER include:

- a refusal of oral feeding
- apnea (period of non-breathing)
- arching of the back

Premature infants also have very immature immunological systems and therefore are at an increased risk for infection. This can lead to poor neurodevelopmental outcomes.

The premature infant is at risk for osteopenia of prematurity. Osteopenia of prematurity is caused by not being able to supply the premature baby with an adequate amount of calcium and phosphorous so the body can make new bone. This can result temporarily in brittle bones that are prone to being easily broken.

The premature infant is at high risk for ophthalmologic problems. Because of the immaturity of the blood vessels in the retina and their exposure to oxygen, they are prone to retinopathy of prematurity (ROP) and may suffer vision loss. Other problems that may occur during their hospitalization include the same physiological problems that occur in term infants such as:

- anemia
- hyperbilirubinemia
- hypocalcemia
- hypo and hyperglycemia
- hypothermia

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**Health Issues Related to Developmental Disabilities**

A developmental disability is defined as a chronic disability that results in a physical and a mental impairment. In contrast, a developmental delay is a lag in one of the developmental areas. A developmental delay may not result in a disability especially if the delay is due to environmental circumstances that are amenable to intervention. A chronic or substantiated developmental disability is usually observed during infancy or early childhood and usually continues throughout the life of an individual. Individuals who have a chronic developmental disability need special supports and services from diverse specialists and interventionists because of functional limitations in several domains.

Infants and toddlers with developmental disabilities are often much more susceptible to health problems due to the limitations in their development. For example, a young child who has restricted physical movement cannot cough and clear his/her lungs as easily as a child who does not have this limitation. A common cold that a typical child can easily manage may represent an issue or catastrophe for this child with decreased mobility. Examples of common developmental disabilities that result in increased risks to physical health include cerebral palsy, Down syndrome, and spina bifida.

It is important for the ITDS to understand the difference between an established condition or disability that is a lifelong condition and a developmental delay that with intervention can show improvement.

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**Eligibility Determination**

Some infants are diagnosed in the neonatal period with a condition or impairment. Other infants and toddlers receive a diagnosis after a thorough examination by health professionals. The established conditions that make a child eligible for Part C services in Florida include genetic and metabolic disorders, sensory impairments (vision and hearing), neurological conditions such as seizures and brain trauma, and severe attachment disorders such as autism.

Children with established conditions that have been diagnosed by a medical doctor or in the case of attachment disorders by a psychologist or psychiatrist are automatically eligible for Part C services. An eligibility evaluation by the Early Steps team is not necessary, only an assessment to plan interventions is required. On the other hand, if there is not an established condition, the child must be evaluated to see if there is a developmental delay.

In the state of Florida, the eligibility criteria for Part C is that a child has a score of 1½ standard deviations below the mean on a norm-referenced test in one area of development. If one of the State approved norm-referenced instruments cannot be administered, the child must be made eligible using a criterion referenced instrument and the eligibility score would need to document a 25 % delay in at least one area of development.

**State Approved Instruments**

The State approved instruments for screening are:

- Ages & Stages Questionnaires
- Early Learning Accomplishment Profile
- Birth to Three Screener

The State approved instruments used for eligibility evaluation are norm- referenced and include:

- Battelle Developmental Inventory II (BDI-2) - both norm and criterion-referenced
- Developmental Assessment of Young Children (DAYC)
- Birth to Three System

*Note*: A criterion-referenced test can be used as a substitute for eligibility determination when the norm-referenced instruments are deemed inappropriate by the team. For example, a child may have a developmental condition that was not included in the normative sample for the standardization of the test. The team may then decide that if the child were assessed using the norm-referenced test, he/she would be compared to a normative group that was not representative of a child with this condition and the criterion referenced test would be preferred.
The State approved instruments for conducting assessments for intervention planning are criterion-referenced instruments including:

- Hawaii Early Learning Profile (HELP)
- Early Learning Accomplishment Profile (E-LAP)
- Assessment, Evaluation and Programming System (AEPS)
- Battelle Developmental Inventory II (BDI-2)

Other instruments used by specific disciplines to capture the diagnosis and plan the intervention strategies are needed when a child has multiple problems more accurately. Sometimes evaluation and assessment instruments must be used that are specific to the suspected problems for the individual infant or toddler. As examples, specific instruments may be needed for infants and toddlers who have hearing or visual impairments or when only a delay in communication is the concern.

**ITDS Role in Testing**

The ITDS becomes a member of the team when the ITDS' disciplinary expertise, education, and experience are suited to meet the concerns expressed by the parents or caregivers for their child during First Contacts. If the ITDS does not have specific expertise in the area of concern, other professionals who provide the intervention for specific populations should be consulted to participate with the team in the evaluation, assessment for intervention planning, and for the interventions. The ITDS must perform within their accepted scope of practice (a set of knowledge and skills required for the profession) identified in Florida by demonstration of the achievement of competencies approved by the Early Steps State Office. Please refer to the service delivery model for Early Steps.

# Infant Toddler Development Training
# Module 6, Lesson 1

**Infant Morbidity and Mortality**

Major indicators of overall health in a population are the rates of infant mortality and morbidity. The rates of mortality and morbidity are measures that are gathered and published as vital statistics. The American Academy of Pediatrics has published these statistics in children since the 1950's. Health goals are often set based on statistics related to these two indicators of children's well-being or the lack thereof. Healthy People 2010 is the most recent health initiative that lists objectives for health planning and goals. A major goal of this initiative is to reduce mortality and morbidity in infants.

US Infant mortality rates published by the American Academy of Pediatrics (2003) show a decreasing trend in mortality:

| Year | IMR | Comments |
|---|---|---|
| 1900 | 150/1000 | Infections, poor hygiene |

| | | |
|---|---|---|
| 1914 | 100/1000 (10 %) | Pre-antibiotics |
| 1936 | 57.1/1000 | Some antibiotics |
| 1950 | 29.2/1000 | New technology, more premature infants living, increased morbidity |
| 1957 | 26.1/1000 | Widespread use of penicillin, sulfa, streptomycin |
| 1980 | 12.6/1000 | Prematurity the leading cause of death at 50 - 60% Congenital anomalies at 20 - 25% Stillbirths at 10% |
| 1990 | 9.2/1000 | Teen birth rate dropping for the 15 - 19 age group |
| 1995 - present | 6.9/1000 | Disparity of different populations Teen birth rate dropping for the 15 - 19 age group |

*Infant Mortality Rate (IMR) is the number of deaths in comparison to live births.

The most recent vital statistics are reported in the Morbidity and Mortality Weekly Report (MMWR) that is published by the Centers for Disease Control Figures are based on the 2000 census data. There is a trend over the past decade that documents a decline in the birth rate in the United States that is now 13.9 births in 1000 women of childbearing age. This rate results in a positive population balance. There has been some decline in the number of births to teen-age mothers.
Infant mortality in the United States is stable at 6.9/1000 infants. There continues to be disparity between cultural groups with higher mortality figures for the African American and Hispanic populations. Figures can be found at Centers for Disease Control Florida's vital statistics and information on health issues may be found at Florida Department of Health or the expanded link to the vital statistics information for Florida at Florida Department of Health Vital Statistics.

**Common Causes of Infant Morbidity and Mortality**

Examples of morbidity include respiratory conditions, impairments of speech or intelligence, nervous or mental health conditions, nonparalytic orthopedic conditions, diseases of the eyes or ears, and congenital anomalies. These conditions put an infant or toddler at higher risk for chronic disabilities or even death. The following are common causes of morbidity and mortality.

**Congenital Anomalies** are conditions that are present at birth that manifest in a structural defect. These include those that are visible such as a cleft lip or imperforate anus and those that are not visible to the naked eye such as the absence of the corpus callosum of the brain.
**Neonatal Infections** include bacterial sepsis, and viral infections in newborns. These infections affect infant morbidity and mortality. They have continued to be one of the leading causes of infant mortality for the last twenty years. Antibiotics may sometimes treat bacterial infections, but the immature immune status of the neonate makes it very susceptible to overwhelming infection.

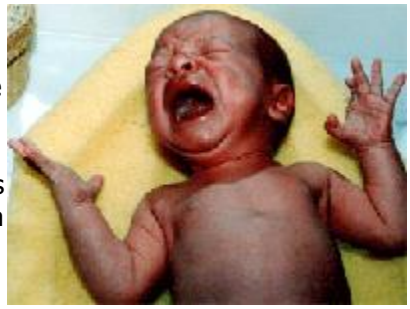
- Bacterial sepsis is a significant cause of morbidity. The early onset of a group B strep infection causes pneumonia, sepsis, meningitis, persistent pulmonary hypertension of the newborn, and hypoperfusion and can result in organ damage and death. The same issues can occur with other bacterial infections and cause similar sequelae in older children.

- Viral infections can infect the mother in any trimester and cause a variety of sequelae to the newborn. Examples include rubella, measles (rubeola), varicella, herpes simplex, cytomegalovirus, and parvoviruses. Though there are characteristic findings for each virus, all incidences in the first trimester can cause miscarriage; all in the second trimester can cause growth issues and many cause sensory organ damage. Some infants when infected during the birth process to cytomegalovirus (CMV) may not show immediate problems but may develop problems such as progressive hearing loss. Their hearing loss may be manifested over several years making detection and follow-up crucial.
- Neonatal exposure to sexually transmitted diseases may cause problems for the newborn. Examples include syphilis, chlamydia, gonorrhea, and human immunodeficiency virus (HIV). All may result in significant morbidity and mortality.
- Diseases due to parasites, though more common in children from third world countries, contribute slightly to the morbidity and mortality in infants. The major exception of a parasite in the United States that can have a devastating effect on the infant is toxoplasmosis. The pregnant woman may become infected primarily through touching anything that has come into contact with contaminated cat feces. Pregnant women are advised NOT to change litter boxes. However, they may reduce the risk of infection with good hand washing and wearing gloves if they do change litter boxes, dig in garden soil, or handle raw meat

**Low Birth Weight (LBW)**, <2500 grams, and especially very low birth weight (VLBW), <1500 grams, contribute to the causes of morbidity and mortality. Although the gestational age of viability and survival has dropped over the years, technology does not ensure complete well-being. Premature births, particularly for infants of very young gestational age, still contribute to significant morbidity.

**Sudden Infant Death Syndrome (SIDS)** is a cause of death for both neonates (first 30 days of life) and for infants. The cause is unknown, but there are measures such as putting babies to sleep on their back that have been shown to reduce the incidence.

**Substance Exposed Newborns (SEN)** are also at higher risk for morbidity and mortality. A mother's use of tobacco, ethanol (alcohol), cocaine, or other illegal drug can have a significant effect on the baby because they harm the integrity of the placenta. The infant may suffer withdrawal, be smaller for gestational age, and have fewer fat reserves. They may be at risk for hypertension, diabetes, and later learning and behavioral problems. There are also prescription drugs that contribute to the overall numbers of infant mortality or morbidity and can negatively affect the baby.



**Metabolic Abnormalities** contribute to the IMR. For example, hyperbilirubinemia (high bilirubin levels) if untreated may result in a condition known as kernicterus (bilirubin in the brain) and can lead to seizures, intracranial hemorrhage, death, and if the infant survives, can cause mental retardation. While there are treatments for high bilirubin levels there are still casualties. Children who have hyperbilirubinemia are also at risk for hearing loss. Another common metabolic condition seen in the NICU is hypoglycemia (low blood sugar) which can lead to seizures and brain injury if severe or prolonged.

**Seizures** are a sign of brain dysfunction and have a variety of causes including hypoglycemia (low blood sugar), hyponatremia (low sodium concentration), hypocalcemia (low calcium), hyperbilirubinemia, hypoxic-ischemic encephalopathy (HIE), infections (meningitis and encephalitis are examples of inflammation of the membrane coverings

surrounding the brain), trauma, malformations, and intracranial hemorrhage. Seizures in the newborn period are often not full-blown and their symptoms may be subtle. However, the seizures can be generalized as well as partially complex, or focal in distribution. **Injuries** from falls, vehicle crashes and pedestrian accidents account for approximately 3.3% of deaths in young children, including toddlers. Drowning is also a significant safety factor for infants and toddlers. The ITDS should be alert to preventive measures such as never leaving a child unattended at bath time or around open water buckets, open toilet bowls or bodies of water.

## Infant Toddler Development Training
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**Effect of Health Problems on Families**

The ITDS should have an acute awareness of the societal changes in the demographics of families. He/she must be very respectful of the differences in cultural as well as individual responses to challenging situations. A family can be defined as a single parent, either by choice or by death or divorce, a blended family, or may consist of multigenerational members. Children now are often raised by parents with alternate lifestyles, foster or adoptive parents, grandparents, or other kin, or by non-relatives.

For many families a major impact of having an infant or toddler with a developmental disorder or chronic health condition is considered the loss of the dream. A typically developing robust child may not be a reality. When this occurs, each family member must cope and adjust in his/her own time and way.

The perceptions of the family can be influenced by all the following: the visibility of the condition, the functional limitations that are expected for the child, the presence or absence of cognitive impairment, the presence of pain and suffering for the child, and the expectations that family members had for the child.

**Stresses on Mothers**

In many families the burden of care for a child with special needs and chronic health problems falls to the mother. This can include responsibility for special diets, arranging transportation, medical care, adaptive equipment, medical financing, babysitters, and loss of time at a paying job. Additionally, the presence of functional and cognitive limitations in a child are linked to increased stress in mothers.

**Chronic Sorrow**

Some family members may experience chronic sorrow. Olshansky (1962) first identified the notion of chronic sorrow in families who have children with special needs. Chronic sorrow does not imply that families who have children with special needs are not normal and do not enjoy typical family activities. Rather, it refers to the fact that incidences such as visits to specialists for a diagnosis or planning meetings for services may bring up earlier grief reactions.

**Searching for Information**

Often families will search extensively for information about their child's condition and sometimes may neglect the emotional needs of the child's siblings or others in the family. The number of children who do not have an actual diagnosis of a chronic disability is estimated to be around 30%. This is very frustrating to families who want to know the cause, as well as the possible treatments. Assisting families to find the appropriate specialist to establish a diagnosis is important. Practitioners who label a child without first establishing

causation may contribute to the stress that families feel. It should be noted, however, that for a small percent of children, a definitive diagnosis and causation will never be made.

**Financial Pressures**
The family is also dealing with the pressures of an added economic burden because of the cost of the health care, particularly if the child needs the services of multiple specialists. This includes the financial burden and expenses that are not usually covered by most third-party payers.

**ITDS Awareness**

The ITDS should be attuned to adjustment concerns and use reflective listening strategies to assist families going through a difficult time without judging what sometimes may seem like irrational mood swings. For example, sometimes a parent may lash out at a provider, yet their anger is not directed at the person but rather they are displaying anger because they feel a helplessness to cure the child or better a situation. The ITDS must be alert to opportunities when positive feedback on the parents' competence can be provided to enhance the capacity of the parents to feel a sense of competence in their care giving skills. Families who feel competent adjust much more readily to parenting a child with special needs.

Not all families welcome extensive interventions as some view visits and strategies as an intrusion. How does the team make adjustments that show respect for a family who expresses this concern?

What other special circumstances could the ITDS encounter where adjustments in location, duration, and frequency or types of support vary?

## Infant Toddler Development Training
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**Financial Constraints and Resources**
The decrease in infant mortality rates has resulted in an increased morbidity rate that is now impacting the financial picture of the health care industry. Many young children have some type of chronic illness. Approximately ten percent (10%) are classified as disabled. This has created financial concerns and constraints for how to provide care within budgetary guidelines. Resources have needed to adjust and plan accordingly.

**Managed Care and Other Insurance**
The state agency for children with special health care needs is Children's Medical Services (CMS) which is a division of the Department of Health. CMS is a managed care organization that provides care for children birth – 21 years with chronic medical conditions who meet financial criteria. Through CMS, care is provided for children with Medicaid and others under a share of cost arrangement. Managed Care Organizations, such as CMS, became popular around the 1980's. They limit the coverage of medical expenses by limiting the services they will cover. The rationale is cost containment and efficiency while also maintaining quality of care.

Florida, in recent years, developed a program for insurance coverage for families of children who cannot afford insurance. This program is Florida KidCare.
**Agency for Persons with Disabilities and Other Resources**

The ITDS should provide families who may qualify with information about the Agency for Persons with Disabilities (formerly Developmental Services). Even though a child under age 3 will be put on a waiting list due to the large numbers of families in need of support, the information should still be provided. Additionally, the ITDS can provide the family with information about Medicaid and the Supplemental Security Income (SSI) program for children with disabilities who meet financial eligibility. Information about these programs is available by visiting the appropriate website at the end of this lesson.

Why is it important for the ITDS to share information about the Agency for Persons with Disabilities?

What other financial resources can the ITDS share with families who have children with developmental disabilities?

# Infant Toddler Development Training
# Module 6, Lesson 1

**Medical Ethics / Confidentiality**

Medical ethics is a system for making decisions used by medical practitioners. Ethics include weighing factors logically and considering morals and values. Underlying medical ethics is the premise that the physician or practitioner has a duty to 'first, do no harm', and show respect for persons. Principles in medical ethics include:

- a belief that people are autonomous and can practice self-determination
- a responsibility to tell the truth
- a duty to keep one's word
- a sense of justice and fairness
- consideration of issues of privacy and confidentiality
- strategies for dealing with conflict and disagreements

When medical ethics is applied to children, the physician or practitioner asks questions such as who needs to make the decisions for the child. Often the decision maker is the parent, but sometimes it is a care provider, or a surrogate assigned by the state if the child is in special foster care.

It is important for the ITDS to recognize the medical home of the child and to work in concert with this primary provider of health care. The ITDS should not give advice to the family that will confuse or jeopardize care. Whenever possible the primary medical provider should be included as an active participant and consultant on the IFSP team.

All persons who work in health-related fields are responsible for maintaining confidentiality. The privacy laws that pertain to the protection of educational and health records bind the ITDS. This includes the Family Right to Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA). Examples of privacy protections include that all records of the ITDS should be maintained in a locked file. No personally identifiable information for the child and family should be transmitted by electronic means. Additionally, the ITDS should not discuss a child or family without the express written permission of the family and only for specific purposes that have been identified and agreed upon by the family. This requirement is important when planning consultation visits and staffing sessions.

# Infant Toddler Development Training
# Module 6, Lesson 1

**Activity #1**
Consider this scenario.

You are an ITDS working with Nancy who is 18 months old and has mild motor delays and chronic lung disease. Her mother tells you that Nancy has had no immunizations since her first set at the age of 2 months. Mother relates that she does not have health coverage for Nancy and the family appears to not be able to purchase such.

Your first course of action would be to discuss the situation with the mother and the service coordinator to work toward linking this family to a primary care provider and explore the insurance options for the family such as the KidCare network.

The ITDS may also suggest and assist as needed with placing calls to the County Public Health Department for information on free or reduced immunization programs for disease prevention.

**Question 1** - What valid information can you provide to this mother related to health care programs including immunizations?
This is useful information to share with the child's family. Even more important is ensuring that the family gains access to a medical home for the child. Explore the options for KidCare and Medicaid with her and assist, as needed, with applications. Websites which the mother and ITDS could explore together include

- Florida KidCare
- Family KidCare
- MediKids

**Question 2** - What other information could you provide that may assist this family using electronic resources such as the internet?
The following are excellent resources.

- American Academy of Pediatrics (AAP)
- Centers for Disease Control
- Bright Futures
- KidsHealth

A site that provides modules related to maternal and child health including growth and development, and nutrition is Maternal and Child Health Library. The site links to many other sites such as the Centers for Disease Control which provides growth charts that can be downloaded free of charge.

**Activity #2**
Read the following criteria for assessing valid clinical information that includes a rigorous process of

- information with an extensive literature review
- material subjected to a stringent supervised peer review process
- feedback and correction
- hypothesizing and research design to determine the validity of the hypothesis

Consider this scenario.

When visiting Ms. S. and her 3-month-old son Sammy, who has Down syndrome, the ITDS is asked by Ms. S. whether it would be okay to start her son in a "Mommy and Me" Gymboree class. Ms. S. says she thinks this would be good because this is a place where Sammy could do things with peers his age. She has visited some websites for Down

syndrome on the internet and has seen that many children with Down syndrome attend Gymboree. Ms. S. shows the ITDS one of the articles she has read.

Based on the reading you completed for this activity, reflect on the criteria for assessing valid clinical information. Given the criteria, how should the ITDS answer this mother?

First and foremost, the ITDS should refer Sammy's mother to discuss the issue with Sammy's primary medical provider. The primary medical provider is often a pediatrician or a family practitioner. However, the primary medical provider may be a nurse practitioner that works with a clinical practice to provide a medical home (hub of medical care) for the child. Sammy may have health conditions that would preclude his participation. This may include a cardiac condition, joint laxity, or other condition that the children represented in the article did not demonstrate. Additionally, the ITDS will want to ensure that Sammy's service coordinator and provider team are aware of Ms. S.'s desire for more community-based opportunities for Sammy. The ITDS should ensure that additional supports are added to the Individualized Family Support Plan (IFSP) and the case notes.

**Activity #3**
Go to the list of websites at the end of this lesson. Locate some that provide information on statistics related to health and disease including health initiatives such as Healthy People 2010. Look for statistics on infant mortality and linked files on death and causes of death.

Identify websites where information on vital statistics can be found. Answer these questions based on the information you find. What is the number of live births in Florida? What are the leading causes of infant mortality?

Note: Questions about the categorical breakdown of information provided on the website relating to infant birth and death rates may appear on the Self-Assessment and/or Final Evaluation.

## Infant Toddler Development Training
## Module 6, Lesson 1

**Highlights**
This lesson provided the ITDS with an introduction to health and disease in infants and toddlers including definition of terms. The basic priorities of newborn development and care were reviewed. Health issues relating to premature births were explained. The ITDS is reminded to make a neurological correction for children until the age of two years to adjust for prematurity when calculating scores on developmental assessments.

The relevance of feeding issues for the newborn and infant were summarized. Infant morbidity and mortality were explained with the major causes cited. The impact on the family, the cost of health care, and ethics related to the provision of care for infants and toddlers with medically complex conditions and/or intensive special needs were briefly summarized. The ITDS was reminded that all infants and toddlers need a medical home to serve as the hub of their medical care and record keeping. Website links to relevant information were provided for expansion of ideas presented in the lesson.

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**Websites**

- Agency for Persons with Disabilities
- American Academy of Pediatrics - This is the home page for the American Academy of Pediatrics.
- American Academy of Pediatricians - AAP Policy on Breastfeeding
- Bright Futures - A program of Georgetown University
- Centers for Disease Control - Provides statistics on birth and death rates, Healthy People 2010, and other health related initiatives.
- Childbirth Organization - This site provides information on the Apgar scale.
- Children's Medical Services Homepage - Children's Medical Services in the Department of Health is Florida's agency that serves children with special health care needs. The ITDS should be familiar with this homepage related to children with chronic health care needs so that information can be shared with the family. Early Steps in Florida is provided as a program of Children's Medical Services.
- Clinical Evidence - Provides articles related to clinical medical practice and gives an overview of what the editors who choose medical articles for this web site consider when making judgments of valid medical research to include on the web site.
- Early Steps - Early Steps is an early intervention program of supports and services provided to enhance the caregiver's capacity in the developmental care of the child.
- Family KidCare
- Florida Department of Health - website provides information on birth and death rates as well as information pertaining to prevention programs such as immunizations and other health issues relevant to the infant and toddler.
- Florida Department of Health Vital Statistics - provides expanded information on various categories of vital statistics. Learners will want to print the neonatal birth and death rates for Florida.

- Florida's Developmental Disabilities Council
- Florida KidCare - this site contains helpful information on health care resources that are available to families who lack insurance for their children.
- Florida KidCare (Spanish) - this site is written in Spanish and contains helpful information on health care resources that are available to families who lack insurance for their children.
- Florida's Healthy Start Program - Healthy Start is a program for pregnant women and for infants up to three years of age who have increased risk for medical or developmental problems.
- Immunization Schedule
- MediKids
- Kids Count – Kid Count from the Annie E. Casey Foundation
- Kids Health – A large bank of health-related resource articles that are specifically written either for parents, teens, or children.
- La Leche League – Provides information on breastfeeding
- Maternal Child Health Library
- Mental Health – Provides information related to mental health
- SIDS Organization – All the SIDS web pages provide information related to Sudden Infant Death Syndrome
- SIDS Alliance
- SIDS Center

# Infant Toddler Development Training
# Module 6, Lesson 2

**Introduction**

In this lesson, information will be presented relative to generally accepted growth stages and nutrition of infants and toddlers including conditions that impede normal growth. Specifically, the lesson provides the Infant Toddler Developmental Specialist (ITDS) with information pertaining to nutritional risk; the prevalence rates of obesity and undernourishment; and signs and symptoms of nutritional disorders for specially designated conditions.

The ITDS will enhance his/her knowledge and skills as a member of a multidisciplinary or trans-disciplinary team that may consist of the primary medical provider, the behavioral specialist, and a nutritionist to effectively plan and implement a Nutritional Plan of Care with the family. However, individual expertise varies across the state and all areas may not have access to a nutritionist or behavioral specialist. Each team will need to identify the professionals from their area that have expertise related to these concerns. For example, in some areas it may be a physician, a psychologist, or an educator. For sensory issues it may be an occupational therapist or a speech language pathologist. Issues of nutrition related to behavioral challenges are addressed for the ITDS.

This lesson presents the ITDS with strategies to assist families in the promotion of dental health and preventive health, including immunizations that were briefly introduced in Lesson 1. The lesson reviews the basics of cardiopulmonary resuscitation (CPR) and seizure precautions. It provides an overview of the common acute illnesses of childhood that may be seen in infants and toddlers.

**Learning Objectives**

Upon completion of this lesson, you will be able to:

1. Cite the prevalence rates and associated growth and nutritional risks for undernourishment and obesity.
2. Define nutritional factors associated with specially designated diagnoses in infants and toddlers.
3. Assist with assessment related to infants and toddlers who are medically complex or have low incidence disabilities.
4. Understand the terminology in a doctor or nutritionist's report related to anthropometric assessment.
5. Assist the family in the application of interventions prescribed by the primary medical provider or nutritionist.
6. Participate as a member of the multidisciplinary team to address behaviorally based feeding disorders and assist the family in implementing a Nutritional Plan of Care using a behavioral approach.
7. List and recognize the symptoms and signs of inadequate caloric intake and losses, other nutritional risks, and the physical signs of a nutritional disorder.,
8. Work with the multidisciplinary team of professionals including the primary medical provider, the nutritionist, and the family to ensure generalization or integration of the Nutritional Plan of Care within the family's cultural beliefs and everyday activities.
9. Review immunization schedules for infants and toddlers with families.
10. Recognize the symptoms of seizures and explain precautions to families.
11. Explain dental care for infants and toddlers.
12. Recognize the symptoms of acute illness in infants and toddlers.

**Resources**

The following resources are necessary for the completion of this lesson. Learners may wish to access and print a hard copy of the resources prior to beginning the lesson and for future reference. Some resource documents can be found in the Resource Bank. Others are available online.

- A Primer on Preemies
- Allergic Reactions
- Bites and Scratches
- Burns
- Common Diagnoses in the NICU
- CPR
- Cuts
- Facts and Myths about Immunizations
- First Aid and Safety
- Food Insecurities
- Florida's Individualized Family Support Plan (IFSP)
- Looking at Metabolism
- Plan of Care
- Seizures
- Sunburn Fact Sheet
- Teething Tots

**Center for Disease Control Growth Charts**

- Weight-for-age percentiles: Boys, birth to 36 months
- Weight-for-age percentiles: Girls, birth to 36 months
- Length-for-age percentiles: Boys, birth to 36 months
- Length-for-age percentiles: Girls, birth to 36 months
- Weight-for-length percentiles: Boys, birth to 36 months
- Weight-for-length percentiles: Girls, birth to 36 months
- Head circumference-for-age percentiles: Boys, birth to 36 months

- Head circumference-for-age percentiles: Girls, birth to 36 months
- Weight-for-age percentiles: Boys, 2 to 20 years
- Weight-for-age percentiles: Girls, 2 to 20 years
- Stature-for-age percentiles: Boys, 2 to 20 years
- Stature-for-age percentiles: Girls, 2 to 20 years
- Weight-for-stature percentiles: Boys
- Weight-for-stature percentiles: Girls
- Body mass index-for-age percentiles: Boys, 2 to 20 years
- Body mass index-for-age percentiles: Girls, 2 to 20 years

**Down Syndrome Growth Charts**

- Boys Length - Birth to 3
- Boys Weight - Birth to 3
- Boys Height - Age 2-18
- Boys Weight - Age 2-18
- Girls Length - Birth to 3
- Girls Weight - Birth to 3
- Girls Height - Age 2-18
- Girls Weight - Age 2-18
- Boys Head Circumference - Birth to 3
- Girls Head Circumference - Birth to 3

**Key Words**

Definitions of key words are found in the glossary.

- Anthropometric
- Biliary Atresia
- Bradycardia
- Endocrine Disorders
- Esophageal Sphincter
- Fiberoptic Endoscopic Evaluation of Swallowing (FEES)
- Infantile Anorexia
- Naso-duodenal
- Naso-gastric
- Naso-jejunal
- Orogastric
- Percutaneous Endoscopic Gastrostomy (PEG)
- Stadiometer
- Swallow Apnea
- Tracheostomy
- Videofluoroscopic Swallow Study (VFSS)

# Infant Toddler Development Training
# Module 6, Lesson 2

**Nutrition**

**Epidemiology**

The overall prevalence of nutritional disorders for children eighteen years of age or less in America includes obesity at a rate of 25% and undernourishment at a rate of 10%. Of note is that 70% of infants and toddlers who have been diagnosed with special health care needs demonstrate at least one of the risk factors for a nutritional disorder and 40% have a diagnosed nutritional disorder. The ITDS can find information about nutrition in children including data from the National Health and Nutrition Examination Survey

When the ITDS, as part of the early intervention team, encounters a child who appears undernourished or obese, the ITDS must first determine whether the child has a primary medical provider. If there is no primary medical provider, the family should be connected to a primary medical home as well as a pediatric nutritionist as indicated to develop a collaborative nutritional plan of care that includes ongoing follow-up with medical providers. The Plan of Care, as part of Florida's Individualized Family Support Plan (IFSP) must be written with the family so that they may integrate or generalize activities into mealtime routines and other community and social and cultural activities.

**Undernourishment**

Infants who are undernourished follow a growth trajectory that shows decreased linear growth and an increased susceptibility to infections. Sometimes it is hard to determine if the undernourishment is due to an organic condition or if it is related to developmental and behavioral delays associated with poverty or neglect.

Infants who are undernourished demonstrate slightly decreased differences in cognition and in motor development. If the undernourishment is associated with iron deficiency anemia, then the child becomes significantly at risk for possible cognitive delays. If an adequate nutritional source can be established and if the relationship between the infant and caregiver can be optimized, then often the undernourished infant can thrive. The ITDS should be alert to this important relationship and be prepared with strategies to positively enhance the feeding time environment.

Undernourishment is also seen when calories are used faster than for typically developing children of the same age. Being active as a toddler is not a cause of weight loss because this is typical behavior at this age. Some causes that may be associated with excess utilization of nutrients include:

- recurrent infections
- chronic respiratory insufficiency
- congenital or acquired heart disease
- malignancy
- toxins such as lead and drugs
- endocrinology disorders such as hyperthyroidism

**Low Birth Weight and Nutritional Status**

Low birth weight, especially at full term, as a single factor may not be indicative of nutritional risk. A smaller maternal size has been related to smaller infants. This does not necessarily mean that the infant has low birth weight. The infant must be assessed in the context of cultural factors or accompanying growth and nutritional risk factors. The smaller size of the infant may only be indicative of the genetic endowment. The primary medical provider will monitor the growth of the infant closely to ensure that the length for weight index documents proper growth. Infants born with low or very low birth weight due to prematurity or other pre- or post-natal conditions must have their nutritional needs assessed in context with their specific medical needs.

**Obesity**

Obesity or the condition of being overweight is associated with an increased risk of cardiovascular concerns, diabetes, decreased mobility, and social implications as the child grows. There is also an associated challenge for the caregivers if the child is non-ambulatory

past the age in which typical peers would be walking. As mentioned earlier, the child must be in the care of a primary medical provider and with a pediatric nutritionist if indicated.

There are certain syndromes that have associated risks for obesity and require monitoring often by a developmental pediatrician and a pediatric nutritionist. Two of these are Down syndrome and Prader-Willi syndrome. These will be discussed in this lesson in a section relating to genetic and endocrine disorders.

## Infant Toddler Development Training
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**Nutritional Risk and Assessment**

The presence of any indicators of nutritional risk warrants a nutritional assessment by the primary medical provider. The primary medical provider generally monitors nutrition as part of routine care. This is even more important for the child with chronic health conditions. The pediatrician or primary medical provider may refer a child with chronic feeding issues or several nutritional risks to a pediatric nutritionist. Indicators of nutritional risk include altered growth, altered appetite, and medications that alter the appetite or interfere with the absorption or excretion of nutrients. Other risk factors related to nutrition are an increase or decrease in energy needs, metabolic disorders, impaired mobility, decreased cognitive functioning and increased cardio-respiratory or physical effort. Another risk factor is the documentation of poor feeding skills by either the caregiver or child.

While visiting the home or childcare site, the ITDS should be alerted to lead poisoning risks such as peeling paint in older homes or play areas consisting primarily of loose dirt without grass or other covering. Screening for lead exposure should be part of the routine medical care for all infants and toddlers. Preventive steps include frequent hand and toy washing and provision of snacks high in calcium, iron, and vitamin C as children with empty stomachs or poor diet absorb more lead. High blood lead levels have been associated with learning disabilities, anemia, hearing loss and behavioral problems.

**Medical and Feeding Histories**

Nutrition is assessed by monitoring the child's growth rate over time and by an analysis of the medical and feeding histories. The medical history will include illnesses and medications. The feeding history includes food content and caloric intake and excretory output, developmental feeding skills, daily routines related to feeding, and the environment where feeding occurs. Not only is history important to establish a baseline, but the history also can provide clues to causes of nutritional and/or feeding difficulties.

When taking a feeding history, it is important to ask:

1. How much?
2. How often?
3. What types?
4. Feeding routines?
5. Where does feeding occur?
6. Who is the primary feeder?
7. Are there difficulties with feeding such as choking, gagging, coughing, vomiting, or ruminating with certain foods and not with others?
8. Does the child refuse certain foods or is the child overly selective with great restriction of food types?

9. Does the child refuse foods of certain textures?
10. How long and when did feeding issues begin or occur?

**Physical Exams and Laboratory Tests**

The physical exam and any laboratory tests follow the history. The physical exam includes growth parameters such as length or height and weight. The developmental history and assessment are as important as the physical exam and history when assessing for nutritional risk. The presence of developmental disability or delay impacts what the child may consume. Delays in cognition will usually result in delays in adaptive skills such as finger and spoon feeding and moving from liquids to solids.

**Social and Caregiver History**

After obtaining a nutritional history and performing a physical exam of the infant or toddler, the primary medical provider will take a social and caregiver history to ascertain if there are maladaptive beliefs about food. The physician is also informally assessing the caregivers' ability to understand a nutritional plan and medical advice. The physician may be considering questions such as:

- Are there factors of cognitive ability related to the caregivers?
- Are there financial strains in the home?
- Is there support for the primary caregiver (usually the mother but not always)?
- Is there history of substance abuse or is there a physical or mental condition of the caregiver that could impact the nutritional well-being of the child?

The physician also needs to ascertain if there are genetic patterns that are common to the family such as short stature. Gathering this information would help the physician determine whether this could be a genetic indicator or if malnourishment is a concern. The ITDS may also explore and discuss cultural beliefs in a sensitive manner to determine if these values are compatible to the nutritional plan of care.

Even in the United States there are families who do not have enough food to eat. To learn the percentage of families who experience the lack of food necessary to maintain a healthy lifestyle please go to Food Insecurities for a required reading.

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**Physical Signs and Anthropometric Assessment**

Assessment of growth parameters such as weight, height, and the relationship of weight for height and monitoring for the rate of growth over time by plotting gains and/or losses on a growth chart is the most common physical evidence used in monitoring nutrition and growth. Additionally, the primary medical provider monitors head circumference and checks to see if there is enough subcutaneous fat under the skin to indicate nourishment status. Cutaneous factors such as thin dry hair, dry skin, oral lesions, or nail beds that are discolored, thin, or ragged can also be an indicator of nutritional problems. The importance of the head circumference is that the size of the head is often indicative of brain growth.

Accurate measurement of growth is extremely important. Infants and toddlers who have suspected growth risks or nutritional problems need to be followed closely. They should be weighed nude as clothes and shoes can contribute up to ½ pound for the infant and up to 2 pounds to the weight of an older child. A stadiometer should be used for checking the length

and height. Plotting on the appropriate growth chart is very important. Length measured with the child lying down is plotted on a 0 – 3-year-old growth chart and height measured with the child standing flat is plotted on the 2 – 20-year-old growth chart. The weight for height called the body mass index (BMI) should also be plotted as it provides a rough estimate of body bulk that includes muscles, fat, and bones. The nutritionist will routinely measure the triceps skinfold for fat content and the mid-arm muscles to assess for muscle mass.

The Centers for Disease Control (CDC) in the United States provides growth charts standardized on the general population.

Print copies of the following male and female growth charts for the 0–3-year-old and for the 2–20-year-old if you have not already done so when you began this module.

**CDC Growth Charts: United States**

- Weight-for-age percentiles: Boys, birth to 36 months
- Weight-for-age percentiles: Girls, birth to 36 months
- Length-for-age percentiles: Boys, birth to 36 months
- Length-for-age percentiles: Girls, birth to 36 months
- Weight-for-length percentiles: Boys, birth to 36 months
- Weight-for-length percentiles: Girls, birth to 36 months
- Head circumference-for-age percentiles: Boys, birth to 36 months
- Head circumference-for-age percentiles: Girls, birth to 36 months
- Weight-for-age percentiles: Boys, 2 to 20 years
- Weight-for-age percentiles: Girls, 2 to 20 years
- Stature-for-age percentiles: Boys, 2 to 20 years
- Stature-for-age percentiles: Girls, 2 to 20 years
- Weight-for-stature percentiles: Boys
- Weight-for-stature percentiles: Girls
- Body mass index-for-age percentiles: Boys, 2 to 20 years
- Body mass index-for-age percentiles: Girls, 2 to 20 years

When the medical provider is following the growth of children with low incidence disabilities such as Cerebral Palsy, Down syndrome, William's syndrome, Achondroplasia, or others they should plot the growth on specialized growth charts for a comparison to peers with the same condition. Specialized growth charts for Down syndrome, are available below.

**Down Syndrome Growth Charts**

- Boys Length - Birth - 3
- Boys Weight - Birth - 3
- Boys Height - Age 2-18
- Boys Weight - Age 2-18
- Girls Length - Birth to 3
- Girls Weight - Birth to 3
- Girls Height - Age 2-18
- Girls Weight - Age 2-18
- Boys Head Circumference - Birth - 3
- Girls Head Circumference - Birth - 3

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- **Behaviorally Based Feeding Disorders**
- There are four general classifications of feeding disorders: neuro-muscular, behavioral, sensory, and mixed. Neuro-muscular disorders are those that have muscular or anatomic basis. Behavioral disorders are those that are more

psychosocial or interactive in nature. Sensory disorders are those that are a response to specific tastes, textures, or smells. Other disorders are considered mixed because they have aspects of more than one of the classifications.

- There are several sub-classifications of behaviorally based feeding disorders provided by Chatoor (2002). The classification is based on the behavioral characteristics and the age at onset.

| Condition | Age at Onset | Characteristics | Management |
|---|---|---|---|
| Disorder of State Regulation | Newborn period | Infant has difficulty reaching and maintaining a state of calm alertness necessary for healthy feeding | Modulation of stimulation<br>Alternative feeding route<br>Support and counseling for the parents/caregivers |
| Disorder of Reciprocity | Early infancy | Lack of social reciprocity: visual engagement, smiling, babbling during feeding<br>Failure to grow | Multidisciplinary team approach to include physician<br>Home visits<br>Parent training and support<br>Hospitalization as needed |
| Infantile Anorexia | Around time of the transition from liquids to solids and to self-feeding with fingers and spoon | Refusal to eat adequate foods for at least one month in duration<br>Does not communicate hunger<br>No interest in food but explores environment and interacts with caregivers at times other than mealtimes<br>Not related to trauma or illness | Assess infant's temperament<br>Assess for an insecure attachment and parent vulnerability<br>Use a behavioral specialist to develop a behavioral plan that includes structured mealtime routines and to counsel the parents |
| Food Aversions | Early toddler or preschool age | Refusal to eat specific foods with certain tastes, smells, textures, or appearances<br>Occurs during the introduction of a new food<br>Eats better when | Prevention, when possible, by teaching parents about the early introduction of a variety of tastes and textures before the child reaches toddler age<br>Teaching caregivers to model the practice of |

| | | | |
|---|---|---|---|
| | | given preferred food<br>May have nutritional deficiency and oral motor delay | eating healthy foods<br>Instruct caregivers to provide a neutral atmosphere for mealtimes<br>Nutritional supplements and vitamins |
| Disorder associated With Chronic Medical Condition | Occurs when disorder is manifest from newborn period and thereafter | Readily initiates feeding but shows distress over the course of feeding and refuses<br>Medical treatment can improve but not eliminate the problem ails to gain weight or loses weight | Team approach<br>Behavioral management specialist to assist in planning routines and calm atmosphere and to modulate the feeding schedule<br>Oral motor feeding specialist if oral motor dysfunction or aspiration |
| Post Traumatic Feeding Disorder | May occur anytime because of a reaction to a traumatic event or anything that reminds the infant/child of the event | May refuse food following a traumatic or related event such as the insertion of a naso-gastric tube, an episode of choking, severe vomiting, or aspiration<br>May refuse food from one utensil, but accept it from another<br>May accept the bottle, but nothing else<br>May accept offending utensil if sleepy<br>Intense resistance if reminded of the traumatic event | Behavioral management specialist to use extinction behavioral therapy<br>May require supplements to the feeding and may require use of gastrostomy tube feedings until proper nutrition can be managed |

- Behaviorally based feeding disorders are considered in the context of the antecedents or history of behavior. The medical provider and the team, including the ITDS and parents, need to observe what is happening at the time of feeding or mealtimes to plan appropriate intervention strategies.

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**Dysphagia**

A swallowing disorder that may cause nutritional risk is called dysphagia. Dysphagia may occur at different stages in the swallowing process. There are three stages to a swallow:

- **Oral** - the oral phase includes sucking, chewing, and moving food or liquid into the throat
- **Pharyngeal** - the trigger of the swallow reflex occurs during the pharyngeal phase and includes the compression of food down the throat, while closing off the airway to prevent aspiration or choking
- **Esophageal phase** - the esophageal stage begins with the upper esophageal sphincter (UES) opening allowing the food to travel down the esophagus. As the food travels down the esophagus, the lower esophageal sphincter (LES) relaxes allowing the food to enter the stomach.

Pediatric dysphagia includes a wide range of etiologies. These include gastroesophageal reflux disease (GERD) and respiratory disorders. In addition, intracranial hemorrhage, traumatic brain injury, prematurity, and structural abnormalities such as cleft palates can lead to dysphagia and subsequent nutritional concerns.

**Respiration Patterns with Feeding Concerns**

In a clinical evaluation of feeding disorders, respiration patterns are also observed as a potential etiology of feeding difficulties. Continuous nutritive sucking can slow the breathing of healthy infants but is well tolerated. In infants with respiratory compromise, swallow apnea can cause the infant to become bradycardic and hypoxemic. Those children with upper airway obstruction or other pulmonary complications may require a tracheostomy. Unfortunately, the tracheostomy may intensify the dysphagia due to limited laryngeal elevation required during the pharyngeal phase of a swallow.

**Alternative Methods of Food Intake**

The physician for a child who experiences chronic dysphagia may advise the family about alternative methods of nutritional intake for the child. Primary support for short-term nutritional maintenance includes orogastric and nasogastric tubes. Nasoduodenal and nasojejunal tubes are usually used when reflux is present or in long-term feeding problems. Supplemental support can be given through the implementation of a gastrostomy tube. One type of gastrostomy tube is called a percutaneous endoscopic gastrostomy (PEG). A PEG tube is inserted into the stomach allowing the child to be freed of any invasion through the mouth and nose. Oral feeding can be administered with a PEG tube. The various types of feeding tubes are defined below:

- **orogastric tube** is a feeding tube that is inserted into the mouth and through the pharynx, esophagus and into the stomach. This is usually a short term, temporary measure.
- **nasogastric tube** is a feeding tube that is inserted through one side of the nose into the pharynx, through the esophagus and into the stomach.
- **nasoduodenal tube** is a feeding tube inserted into the nasal cavity, through the pharynx, esophagus, and stomach and into the duodenum of the small intestine.
- **nasojejunal tube** is a feeding tube that is inserted into the nasal cavity, through the pharynx, esophagus, and stomach and into the jejunum of the small intestine.
- **percutaneous endoscopic gastrostomy (PEG)** is a feeding tube that is inserted through the stomach using a simplified surgical procedure. This is sometimes simply referred to as a gastrostomy.
- **gastrostomy** is the opening in the stomach created surgically for the purpose of feeding. This is usually a permanent opening.

**Swallowing Evaluation**

There are various techniques available to medical professionals for evaluating swallowing. Each is comprised of advantages and disadvantages. A selection of an evaluation tool is

usually customized to the patient. A fiberoptic endoscopic evaluation of swallowing (FEES) provides detailed information about pharyngeal and laryngeal structures and does not expose the child to radiation. A disadvantage is that it does not assess the oral and esophageal stages of swallowing. FEES is administered through a flexible nasoendoscope which is passed through the nose into the pharynx, allowing visualization of the structures important for swallowing.

Videofluoroscopic swallow study (VFSS) is another way of assessing swallowing. The child is given different consistencies, easiest to hardest for the child to swallow, and they are mixed with either liquid, paste or powder barium. The VFSS assesses all three stages of swallowing and is recorded onto a videotape or still x-rays. Radiation exposure, although minimal, and lack of portability of the equipment are disadvantages of a VFSS.

**Feeding Strategies**
A feeding specialist or a speech-language pathologist with specific additional training and experience can implement treatment strategies. As determined by the team, an occupational therapist as a consultant or direct therapist may address sensory issues relating to foods.

Therapy can be divided into teaching compensatory strategies and/or facilitative strategies. Compensatory strategies can include organizing the infant for feeding, altering the environment, establishing optimum positions, changing feeding utensils, and alternating food consistencies. Facilitative strategies can include establishing a pace and rhythm to feeding, reducing oral aversions, and intervention for behavioral based feeding disorders. The professional will guide and counsel the caregiver to optimize the child's nutritional intake in the home.

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**Inadequate Caloric Intake and Excessive Losses**
Conditions associated with nutritional disorders often interfere with the intake of adequate calories to maintain a healthy body. Poor caloric intake can be caused by a variety of factors. These include poor appetite, chaotic daily routines, and lack of structure in the home. A nutritional disorder can change the metabolic process for digesting carbohydrates, fats, or proteins.

Caloric loss may be associated with reflux, vomiting, diarrhea or constipation that accompanies a disease condition. The body needs a certain number of calories to survive and maintain function. The metabolism or processing of food (nutrients) produces energy that is then expended on cell growth and maintenance.

The metabolism of food creates energy and then the body expends energy. A balance between what goes in and what is expended must be maintained. Simply put, to grow, more calories must go in than are expended.

**Causes of Poor Caloric Intake**
Poor caloric intake can be caused by a variety of factors including poor appetite caused by poor daily routines and lack of structure in the home or stresses that have created anxiety. Poor caloric intake can be associated with central nervous system (CNS) disorders and with chronic or recurrent infections. Medications such as decongestants can also suppress the appetite.

Impairment of oromotor or swallow functions can impede adequate intake and are referred to as neuro muscular. The cause may be organic with muscle involvement for many infants and toddlers who have cerebral palsy. The child may have low muscle tone and the inability to chew properly as is often seen in infants with Down syndrome. There may be cranio-facial anomalies that prevent intake such as with cleft lip or palate and surgical repairs. In these cases, other methods to ensure nutrition must be explored that may include oral muscle strengthening exercises. Alternative routes for nutrition are sometimes necessary such as gastrostomy tube feeding, as defined earlier in this lesson. There also can be an inability to coordinate breathing and feeding which results in dyspnea (difficulty in breathing) and poor caloric intake. The need to address multiple issues may necessitate involvement from a variety of disciplines.

**Food Insecurities**

The issue related to food insecurities must be considered. A food insecurity is the lack of needed food to meet the body's nutritional needs. Food insecurities may be related to psychosocial issues including the lack of finances to support a healthy diet. The team for the family may include a social worker to help the family obtain the food that is needed. The ITDS should be aware of programs such as the Women, Infants, and Children (WIC) program that provide food supplements to low-income mothers and children. WIC is a federally funded program that provides healthy foods, nutritional education and counseling, breastfeeding support, and referrals to needed healthcare services. Information about the program in Florida including referral forms is available through the Florida WIC Program. Food insecurities related to behavior may not simply be the unavailability of food. It may also refer to inappropriate feeding techniques by the caregiver, insufficient volumes of the needed nutrients, inappropriate food for the age of the child, or the withholding of food by the caregiver that is a form of abuse or neglect.



**Nutrition and Special Populations**

The critical period of brain development is during pregnancy and the first few years of life. Malnutrition during embryonic and fetal growth and during infancy and the toddler years influences the developmental outcomes for a lifetime. After birth the greatest rate of growth is during the first six months when an infant will double his/her birth weight. At one year of age a typically developing infant will triple his/her weight. There is a slowing of the growth rate somewhere around nine to fifteen months of age.

All babies should be gaining weight and growing during their first year. If they are not, then something is wrong, and they must be checked and monitored. Contributing causes of problems during infancy include premature birth, the presence of congenital anomalies, cardiac or respiratory problems, and infections. However, vomiting and diarrhea are probably the leading causes of weight loss in an infant.

**Vomiting**

Vomiting may be associated with gastro-esophageal reflux, intolerance or sensitivity to certain foods, an intestinal tract obstruction such as pyloric stenosis (tightened stomach valve that does not allow the passage of food from the stomach into the small intestines) or

malrotation of the bowel. Vomiting may also occur when there is pathology in the central nervous system such as when the intracranial pressure is increased. Vomiting may be caused from the intentional administration of certain drugs such as ipecac that will induce vomiting.

**Diarrhea**

Diarrhea has many causes, the most common being the inability of the intestinal tract to absorb one or more of the necessary nutrients: proteins, fats, or carbohydrates. This condition is known as malabsorption and can result from food protein insensitivity or intolerance or other enzyme deficiency.

The ITDS should be alert to instances when the infant or toddler is not gaining weight or when the caregiver is reporting symptoms of diarrhea. Why is this important to the health of the child?

What awareness should the ITDS have who is providing services to infants and toddlers in childcare facilities related to diarrhea?

## Infant Toddler Development Training
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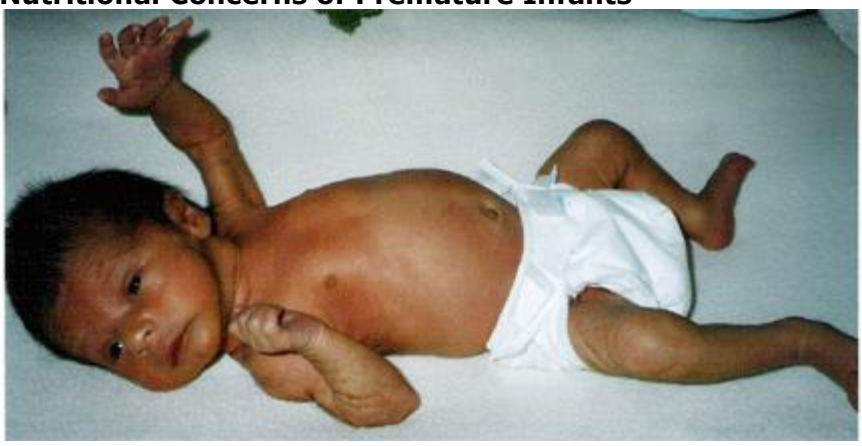
**Nutritional Concerns of Premature Infants**



Premature (pre-term) infants are infants who are born before 37 weeks of gestation. Those born prior to 32 weeks are more vulnerable to nutrition issues. Often pre-term infants have a lower mineral content in the bones which may lead to brittle bones and bone fractures. These infants are at a higher risk for anemia. Premature infants cannot take in as many nutrients as the full-term infant and most of the formulas are based on the daily needs of the full-term infant. Therefore, pre-term infants may need special formulas or supplements in their formulas. Pre-term infants need to have "catch-up" time, usually 9 – 12 months after birth. "Catch-up" refers to the time needed to gain weight more than that expected for their gestational (adjusted) age. Pre-term infants who can be catch-up on weight and growth show improved health and developmental outcomes. Some "catch-up" may occur up to the eighth year of age.

Premature infants need a high nutritional formula at least until they are about nine months old. A nutritionally rich diet, which may include a prescribed, specially enriched formula, or breastfeeding, perhaps with a physician prescribed supplement, is of vital importance during this first year of life. This is when the brain is growing rapidly and making the most neuronal connections.

Premature babies have their weight, length, and head circumference plotted on a growth chart for premature infants. The BMI should always be plotted to ensure growth in body, muscle, and fat. After 9 – 12 months a switch to a regular growth chart can be made if the infant is showing a BMI or weight for length of the tenth to twenty-fifth percentile for a typical infant.

How can an ITDS support young mothers who have premature infants to ensure that the nutritional needs of the infants are met?

Why is meeting appropriate nutritional needs particularly important for premature infants?

**Feeding Environments for Premature Infants**
Studies of premature babies have shown that they do better in a quiet, calm environment where lighting and noise levels are controlled. Even when they must take their feeding through a feeding tube, the infant may learn to self-regulate its neurological state better if they are provided with a non-nutritive sucking experience such as with a pacifier during the feeding. Premature infants sometimes must be fed with a tube inserted through the nose, a naso-gastric tube or a tube inserted through the mouth, an orogastric tube. In some cases, a feeding tube must be inserted directly into the stomach through a surgical opening created in the abdomen. This is a g-tube or gastrostomy tube.

**Weaning from Tube Feeding**
There are several suggested interventions to wean a premature infant from gastrostomy tube feeding to oral feeding. They include:

- Limit the number of caregivers who provide the feeding to the infant.
- Minimize distractions at feeding time.
- Attempt to normalize a feeding schedule with boluses provided after oral feeding has been attempted. A bolus is a small mass of food prepared for swallowing or for insertion into a feeding tube to ensure that an infant receives appropriate nutrients. It is important to note that solid food must be liquefied per a physician's instructions. Usually, a bolus refers to a liquid such as formula or water that is given all at once, rather than via a feeding pump over time. The ITDS should not provide gastrostomy tube feeding unless appropriately instructed by the primary care physician.
- Maintain gentle yet firm and consistent handling during feeding. Premature infants like a firm touch that is not tentative.
- Reward the acceptance of food.
- Ignore refusals of food.
- Remember to use the adjusted age when determining when to start the baby on solid foods.

**Immature Bowels in Premature Infants**
Some premature infants have such immature bowels that they cannot digest food. Sometimes their bowels become necrotic (tissue or cell death) if fed much too soon, if an infection occurs, or if the bowel is malrotated. When necrosis occurs, the infant may require surgical removal of a large portion of the bowel. This is referred to as short gut syndrome. The infant survives with parenteral nutrition. If the infant has lost the ileocecal valve the result is decreased fluid and nutrient absorption and bacterial overgrowth. The physician and nutritionist assist the infant in this situation by introducing oral nutrition when the infant's bowel is more mature. Oral nutrition helps to stimulate bowel growth, and this increases absorption. Hydrolyzed proteins also help absorption. Carbohydrates are often reduced as they cause diarrhea that can result in even more malabsorption.

There are excellent on-line resources for the parent who has a child in the neonatal intensive care unit (NICU). One website provides information regarding nutrition, diagnoses common in the NICU, terminology, and the transition home. Please see Kids Health This site

also provides information on assistive technology and chronic illnesses, such as cystic fibrosis, that affect the nutritional status of children.

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**Chronic Lung Conditions**

Chronic lung conditions are often seen in premature infants and in children with cystic fibrosis. Infants and toddlers with chronic lung conditions have problems with feeding. They may exhibit a poor suck, have fluid intolerance, and experience gastro-esophageal reflux. If they are on diuretics to reduce fluid in their lungs, they also are at risk for the loss of minerals and salts. Their breathing is labored, and this increases their need of energy. They are also at an increased risk of aspiration, particularly if they have shortness of breath. They tend to retain carbon dioxide, and for this reason, carbohydrates should not be increased.

These infants and toddlers tend to exhibit poor growth and need frequent checks by their primary medical provider and often a respiratory specialist. These specialists will monitor their growth and nutritional intake while also monitoring their oxygen needs, the hemoglobin levels, and the levels of other minerals such as calcium and phosphorus. The physician will also be monitoring protein status and the electrolyte balance. Treatment of the gastroesophageal reflux might require medical intervention.

An infant or toddler with a chronic lung condition may fatigue easily. The main role of the ITDS, if involved on the team, is to encourage the caregivers to provide calm, unhurried feedings and monitor to ensure that the infant is allowed to rest if overtaxed. Over stimulation can cause the infant to regress in development and can increase health risks. There may be poor coordination between breathing, sucking, and swallowing and this can result in aspiration. Feeding can become a very negative experience particularly during the transition from liquids to solids

**Chronic Cardiac Conditions**

Chronic cardiac conditions also result in feeding intolerance due to poor suck. There are increased energy needs due to increased respiratory effort. Anorexia or poor appetite and malabsorption of nutrients is common. Chronic cardiac conditions are associated with some genetic disorders including Down syndrome.

**Cerebral Palsy**

Cerebral Palsy is a disorder of movement and posture. The incidence of reduced cognition is also higher in children who have cerebral palsy, however, the two are not necessarily correlated. Nutritional issues may include feeding dysfunction with a poor suck and swallow and decreased motility of the intestinal tract. As with many of the other conditions, the risk of aspiration is greater, as is the risk of gastro-esophageal reflux. There is an associated delay in feeding skills and there are often food refusals that lead to inadequate intake of food.

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**Genetic Disorders**

Genetic disorders and endocrine disorders are common causes of poor nutritional status. Genetic disorders associated with feeding issues include Fragile X syndrome, Down syndrome, Prader-Willi, and William's syndrome.

**Fragile X**

Fragile X is a genetic disorder that occurs in males and females. Males are usually more severely affected. Common characteristics include severe behavioral issues including autistic like behaviors. Associated nutritional issues include hypotonia or low muscle tone that can make feeding difficult. Vomiting may occur and there are often food refusals. There is associated mental retardation usually much more severe in males affected with the disorder than females. To learn more, visit the Fragile X Homepage.

**Down Syndrome**

The most common genetic syndrome is Down syndrome where there is a trisomy on chromosome 21. Information relating to Down syndrome can be obtained through the National Association of Down Syndrome.

Children with Down syndrome usually have lower metabolic rates. This means that they use fewer calories to perform the same activities as their typical peers and this can lead to weight gain and to obesity. Some children with Down syndrome have associated cardiac defects and may have increased respiratory infections. These medical issues delay feeding skills, reduce appetite, and in infancy can result in a failure to gain weight. However, as the medical conditions are treated, and the child grows into adulthood they tend toward obesity unless they are on a program that assists them in an appropriate mix of nutrition and aerobic exercise.

Read Looking at Metabolism by Joan E. Medlen, RD, L.D. and consider the following scenario:

Mary Jo is a 28-month-old who has Down syndrome. She has no cardiac complications. She required ear tubes for multiple ear infections when she was eleven months of age. Other than this, she has been in good health. Her mother asks her ITDS to accompany her to Mary Jo's next visit to see the pediatrician. Mother is concerned that Mary Jo is getting fat. Her muscle tone is mildly hypotonic, but Mary Jo is active and seems to enjoy most of the sensory motor activities that would be expected for a child her age. Mary Jo's BMI was at the 95th percentile plotted on a 0 – 2 female growth chart for typical children when she was 23 months of age.

**Question**: Which of the following would the ITDS expect to hear from the pediatrician?

a. Children with Down syndrome are usually as active as their typical peers.
b. Children with Down syndrome use fewer calories overall to perform the same functions as their typical peers.
c. Children with Down syndrome should have their height and weight measured on growth charts that are appropriate for the general population of children.
d. Limiting calories would be the preferred method of controlling weight in children with Down syndrome.
e. Increasing aerobic activity would be the preferred method of controlling weight in children with Down syndrome if there were no other complicating medical conditions to consider.
f. Mary Jo has a BMI that may be indicative of future problems with obesity.

**Question**: Based on information from the article by Joan Medlen, M.D. (1996) and the content in this lesson, how would the ITDS clarify or expand the information from the pediatrician for the mother?

**Prader-Willi Syndrome**

Another genetic condition where children are extremely vulnerable to obesity is Prader-Willi syndrome. Children with Prader-Willi syndrome usually are compulsive eaters. Children with Prader-Willi may have mild to moderate global developmental delays. Often, they tend to have a condition known as hyperphagia. This means they will eat everything in sight. In addition to the developmental pediatrician, it is recommended that a behavioral specialist work with the family to create a plan so that food intake can be monitored. Resource information both in English and Spanish is available from the Prader Willi Syndrome Association of the USA

**William's Syndrome**

A genetic disorder that occurs in approximately 1 out of 20,000 births is William's syndrome or Williams-Beuren syndrome. There is a defect of the seventh chromosome that can be from either parent. Infants and toddlers with William's syndrome have infantile hypercalcemia, growth retardation, and usually have problems with colic. Feeding issues may also include vomiting and constipation. It is not uncommon for an ITDS to be involved on the team for a child with William's syndrome. It is important to recognize that children with this syndrome are auditory learners as opposed to visual learners. There are issues with attention deficit that will require close collaboration with the developmental pediatrician or psychologist when planning learning strategies and routines to assist nutrition.
The William's Syndrome Foundation has comprehensive information about this syndrome.

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**Endocrine Disorders**

Endocrine disorders are disorders associated with ductless glands such as the thyroid, the pancreas, the adrenals, and the pituitary. Some of the most common endocrine disorders include diabetes and hypothyroidism or hyperthyroidism. Children's Hospital in Wisconsin has a website that is easy to navigate and contains information about numerous endocrine disorders affecting children. Most persons have heard about diabetes. This is a life altering endocrine disorder that affects a person's ability to metabolize carbohydrate due to a malfunction in the pancreas that affects the body's ability to produce insulin. The ITDS should particularly be alert to symptoms of low blood sugar in young children such as the symptoms of disorientation, unusual pallor, and sleepiness.

The over or under production of thyroxin that is the thyroid hormone also causes the infant and toddler to have issues in growth and development and can affect cognitive abilities if untreated. To read about these endocrine conditions in detail go to Children's Hospital and Health System and type in endocrine conditions, diabetes, hypothyroidism or hyperthyroidism.
There are several endocrine disorders that cause nutrition problems in infants and toddlers and the ITDS is wise to access the internet and the local library when a child is referred with a condition that is unfamiliar. All aspects of development including symptoms and common recommended intervention strategies should be researched, if possible, prior to meeting the child and family.

**Management of Nutrition**

A key to managing nutrition is the assessment of developmental and neurological status and involvement of team members to address issues. The team can consist of a pediatric nutritionist, an endocrinologist, a developmental pediatrician, a behavioral specialist, the ITDS, and individual therapists as determined based upon the presenting information for the child and family. The assessment should consist of age appropriateness of feeding skills and the daily routines of the child and family. An assessment of aspiration risk and assessment of gastro-esophageal reflux are specific assessments that may be needed. Remember, the ITDS does not operate outside of the scope of practice for their individual regulated profession but consults with the appropriate specialist together with the family so that everyone is working together to promote the nutrition plan. One program that may be considered by the team to assist in nutritional management and support for an infant or toddler is the Florida WIC Program Applications in English, Spanish and Creole are accessible on-line.

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**Acute Illnesses, Child Care, Prevention, and Intervention Acute Illnesses**
Acute illnesses are those that have a sudden onset and generally have a short duration if treated properly. The ITDS should be knowledgeable about some of the most common acute illnesses seen in infants and toddlers.

**Allergies**
Allergies are a response of the body to foreign agents that are usually proteins. The response is specific to the allergen or agent to which the child is allergic and does not have immunity. The body's response is a mediated reaction using parts of the immune system to ward off the offending allergen. Allergy responses may include a runny or itchy nose and eyes, a cough or wheeze, and airway obstruction if the allergen is airborne and influences the respiratory system.

Some of the common allergens of early childhood include food allergies that may manifest in early infancy. Infants and toddlers may also have allergic reactions to pollen, dust mites, and wasp or ant stings. If the digestive system is affected, the response could include vomiting and diarrhea. If the child has handled or been in contact with an allergen that affects the dermal or skin system, the response may be rashes and welts. A single symptom in isolation does not usually indicate an ongoing allergy.

Infections often appear to mimic allergy symptoms. Whereas an allergic reaction is immediate there may be a gap between the exposure to an infectious agent and the onset of illness. Unless there is an association between an allergen and the response, it is often difficult to ascertain if the child is having an allergic response or is getting ill. The best course of action is to suggest that the child visit the primary medical provider. The ITDS should remember that allergies and infections are both common in early childhood.

If one parent has allergies the chances of a child developing allergies is about 30%. If both parents have a history of allergies there is a 70% chance for the child to develop allergies.

**Allergy Treatment**
Treatment of allergies includes the following:

- Removal of the allergen. For example, if a child is allergic to cat fur, it would be recommended to the family to consider another pet.
- Desensitization to the culprit allergen especially if the allergy has the potential to be life threatening. An allergy specialist who is a doctor that has expertise in this area provides the process of desensitization.
- Medication may be given to regulate the immune system.
- Medication may be given to decrease the response symptoms.
- Medication may be given to repair damage.

Note: The ITDS does not recommend medications. This is the role of the primary medical provider and/or medical specialist.

**Asthma**

Asthma or reactive airway disease is common. Asthma is generally a chronic condition recognized by tightening of the muscles of the bronchial tubes and increased sensitivity of the bronchial tubes or airways. Certain risk factors may be present such as exposure to tobacco smoke pre- or post-natally, a family history of asthma or allergies, or being black or male. Symptoms generally appear at night with a cough and with increased expiratory effort as the airways constrict and swell. Normally the child breathes in longer than breathing out; however, as the episode persists, breathing out becomes more difficult and wheezing occurs. This is because the air is trapped and causes hyperinflation of the lungs.

A trigger is something that creates the onset of symptoms. The trigger may be an allergic trigger or a non-allergic trigger. Non-allergic triggers include infections, dust, smoke, and certain smells. Individuals may trigger because of previous experiences such as an infection or bronchopulmonary dysplasia. Once the wheezing starts it is important to minimize inflammation. The airway remains very sensitive to the trigger for several days to weeks after the initial trigger.

**Asthma Treatment**

Treatment of asthma includes:

- immune system mediators such as cytokine inhibitors and inhaled steroids
- bronchodilators
- oral steroids
- intravenous steroids and oxygen therapy that would be provided in a hospital

All episodes of asthma should be reported to the primary medical provider who will monitor the child and prescribe as needed. Most pediatricians now develop an "Asthma Action Plan" to describe specific actions to take when asthma is present. This plan should be shared with all caregivers, especially childcare staff.

What is the role of the ITDS when working with an infant or toddler who has asthma?

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**Colds**

Colds are the most common upper respiratory infection (URI). Viruses are the usual cause for colds. A runny nose called rhinorrhea and a cough are common especially at night. There is often an initial low-grade fever. Other viral symptoms may also be evidenced dependent on the virus. The rhinorrhea usually lasts from 1 – 2 weeks. The nasal drainage turns from clear to cloudy and is thicker and greener during time. If there is a new onset of fever at the end of the course, it could be a signal that there is a bacterial infection or a new illness and this should immediately by checked by the child's primary medical provider. Complications of colds are otitis media and sinusitis.

**Ear Infections**

Ear Infections can occur in the outer, middle, or inner ears, but are more common in the middle ear. An infection of the middle ear is called otitis media. Otitis media usually occurs secondary to a cold. It may also begin as a response to an allergen. Approximately 33 % of children are prone to otitis media infections and many have three or more infections a year. The first infection usually occurs before 3 months of age. There are also a third of children who almost never have an otitis media infection.

Viruses are the most common cause of ear infections. Bacteria may also cause otitis media including pneumococcus, group A streptococcus, staphylococcus aureus, and Haemophilus influenza. A mycoplasma infection may also cause an otitis media. The symptoms include redness of the eardrum (tympanic membrane), fluid behind the eardrum and/or pus in the external auditory canal. Fluid may continue to be present following the infection. Seventy percent (70%) of children have fluid present 2 weeks after the infection; 40% after 4 weeks; 20% after 2 months; and 10% after 3 months. Fluid causes sounds to be muffled and can affect the acquisition of good speech. Therefore, all otitis media infections need to be followed closely by the primary medical provider or health care practitioner.

**Ear Infection Treatment**

The primary treatment of ear infections includes the use of antibiotics over a period. Sometimes tubes are inserted into the ears if fluid continues for longer than 3 months. This requires the child to be anesthetized while they are inserted. Tubes may occasionally cause scarring and can affect the tympanic membrane. Therefore, a specialist needs to explain the pros and cons of this treatment carefully to the parents.

What should the team consider concerning ear infections related to hearing and speech?

**Diarrhea**

Diarrhea is stools without form and with a lot of water. The cause of diarrhea in infants and toddlers is often linked to food. Diarrhea can be caused by infections with viruses being the most common cause; however, bacteria and protozoa may also be the cause.

Soft, frequent stools may be common in infants who are fed breast milk. These infants may have up to 10 stools per day whereas a formula fed infant may have 1 – 6 stools a day or as few as one stool in three days. A soft, loose stool may be normal if the stool has some form, and the frequency is normal.

If blood is noted in the stool, if the infant appears to be in continuing pain, and if there is weight loss, colitis (inflammation of the bowels) is suspected and should be treated by the primary medical provider immediately. Damage can occur if the diarrhea is severe or prolonged, keeping the intestine from absorbing necessary water and nutrients. Diet can worsen the condition and an infant under the age of 12 months should not be given cow's milk. Infants take up to two weeks to repair damage and toddlers take a shorter period whereas adults only take 2 – 3 days. The intestine is considered repaired if the intestine is

able again to reabsorb water and the diarrhea abates. If gas, cramping, and loose stools persist after the repair period the infant or toddler would still be at nutritional risk of malabsorption. Treatment of colitis is usually supportive. If accompanied by a fever the child may be put on antibiotics. Often a lactose-reduced diet is recommended.

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**Child Care and Group Settings**

Childcare and group settings are where most toddlers and many infants spend their days. Infants and toddlers with special needs are also served in childcare centers or in family childcare homes. The Division for Early Childhood (DEC) of the Council for Exceptional Children recommends that young children with disabilities have access to learning opportunities in their community (Sandall, 2000).
The ITDS has an opportunity to ensure the safety and health of young children with special needs, as well as helping to provide guidance on development, when a child is in a childcare center. Can you think of some ways the ITDS can assist the family in ascertaining the safety of a center?

**Bacterial Infections in Child Care**

Physicians and other health care professionals are concerned about bacterial infections that infants and young children can acquire in childcare settings. Bacterial infections are more prevalent when children are cared for in group settings. Good hand-washing techniques and a clean environment are essential to the overall health of the children and the adults in the center. Encourage the family to inquire about infection control policies. As an example of the higher risk for infection, the National Association of Child Care Professionals provide documentation that children in childcare are at high risk for antibiotic resistant ear infections and are also at significantly higher risk for repeat ear infections. Further information can be obtained through Kid Source.

**Choosing Child Care Settings**

The family has several options when choosing a childcare setting. They may opt for a small or a large family childcare home, a large center, or a drop-in childcare facility. The need for childcare is a discussion that can take place with the team.

If the ITDS is the primary provider, what considerations should be made regarding helping a family access childcare?

**Adult-Child Ratios**

Low adult-child ratios that meet the standards of the National Association for the Education of Young Children (NAEYC) tend to be associated with more developmentally appropriate interactions between the adult caregivers and the children. For infants, the NAEYC recommended practice for adult-child ratio is 1:3; however, licensing allows for 1:4 in most Florida counties. For toddlers, the NAEYC recommended practice for adult-child ratio is no more than 1:6. Lower adult-child ratios contribute to the safety at a center.

**Specialized Child Care**

There are childcare agencies that serve sick children and agencies that serve children with chronic health care needs such as Prescribed Pediatric Extended Care (PPEC) facilities. Children need a physician's prescription to attend a PPEC. PPECs are considered as alternative to home nursing or

prolonged hospitalization. Children served in PPECs need very low adult-child ratios because non-ambulatory children and children with special equipment require a greater amount of time to exit for fire safety and for the provision of routine care giving.

**ITDS Role**
The ITDS assesses the child with special needs in the childcare setting and creates a Plan of Care and a Daily Activity Plan. This is done in collaboration with the childcare provider to support the individual development of the child. The plan is based on the behavioral observations of the child's interactions with peers, adults, and materials in the environment (e.g., toys, books). The ITDS, who is often the Special Instruction Consultant (SIC) for the child, serves as a mentor/coach for the childcare provider who may be a paraprofessional. The ITDS provides examples of ways that teachers can integrate developmental strategies into the everyday routines of the child.

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**First Aid, CPR, and Management of Seizures**
The ITDS will be asked questions by families and childcare staff regarding safety and first aid. The ITDS needs a general basic knowledge of first aid, cardio-pulmonary resuscitation (CPR), and the management of seizures. The ITDS then needs to know where to get information or where to refer families and staff for more information. An excellent web resource is Kids Health.
Please refer to the links below to access the required articles and fact sheets. These are samples of helpful information which the ITDS can share with families.

- First Aid and Safety
- Bites and Scratches
- Burns
- CPR
- Cuts
- Seizures
- Sunburn Fact Sheet

**Bites and Scratches**
Bites and scratches can be sources of infection and disease. Bites from animals can result in rabies or tetanus. Treatment of animal, as well as human, bites must be promptly sought through the child's primary medical provider. Steps to follow for bites and scratches are outlined below.

- If bleeding, pressure is applied using gloves to protect oneself from blood borne disease.
- Clean the wound with soap and water by running water over the wound for five minutes.
- Cover the wound with a sterile pad.
- Call the child's physician.
- Call animal control to capture the animal. Do not try to capture the animal.
- Access the emergency room if the bleeding does not stop, if the wound is deep or longer than a half inch, if the animal was acting strangely, and if any body part was severed. If a body part is severed wrap it in a sterile pad and take it to the emergency room with the child.

**Cuts**
Cuts occur frequently during the toddler years. The same general principles apply to cuts as to scratches. Listed below are things to remember about cuts.

1. Clean the wound with soap and running water for five minutes.

2. If the cut is deep or longer than half an inch seek treatment immediately.
3. If the wound is bleeding, apply pressure and raise the injured part.
4. Do not apply a tourniquet.

**First, Second- and Third-Degree Burns**

Burns are classified as first, second, or third degree. First-degree burns cause redness, pain and swelling, but usually heal well if treated promptly. Second- degree burns blister and are very red. Third-degree burns are very deep and result in nerve damage and disfiguration. The first principle related to burns is prevention. Note the presence of candles, matches, lighters, stove burners, and flammable products in the home or childcare environment and provide cautionary advice. If a child is burned:

1. Remove the clothing unless the clothing is sticking to the body.
2. Run cool water over the burn.
3. You can apply a small gauze pad over the affected area for first-degree burns.
4. If it is a second- or third-degree burn, seek medical help promptly and cover the burned area with a clean, soft cloth.
5. Medical help should also be sought for any burn that is caused by chemicals or electricity and for any burns that involve the face, head, hands, or genitals.
6. If the burn looks very red, swollen, or infected, medical help should be sought.

**Sunburn**

Sunburn is a burn that occurs when children are exposed to harmful ultraviolet rays of the sun. This is the most preventable type of burn and the one often ignored by caregivers. The ITDS, when planning the daily outdoor routines with a family, can assist the caregiver with preventive information. The child needs to be properly clothed with a shirt, hat, and sunglasses to prevent skin and eye damage.

Sunscreen with a minimum sun protection factor of 15 should be applied at least every two hours while the child is outside. Sunscreen with a higher sun protection factor (30 – 45) provides a greater barrier from ultraviolet rays. If the child goes into water, the sunscreen needs to be reapplied immediately upon exiting from the water. If sunburn does occur, the child should be removed from the sun immediately. Cool showers or compresses over the affected area will relieve some of the pain. The child will need extra fluid for a few days to prevent dehydration. Do not put butter, lotion, or crèmes on the burn. The child may need ibuprofen (Motrin) or acetaminophen (Tylenol) but only as directed by the primary medical provider.

**Cardio-Pulmonary Resuscitation (CPR)**

Cardio-Pulmonary Resuscitation (CPR) is mouth-to-mouth breathing in combination with chest compressions necessary to save a life when breathing and the beating of the heart stops. The first step in any situation is to call for help before you begin so someone can place a 911 call. If you are alone making the call yourself as quickly as possible before you begin CPR. In any situation you must then be sure the child is in a safe place to administer the CPR. There are three basic ABCs of CPR:

1. Check the **A**irway to be sure that nothing is blocking the flow of air.
2. Check to ascertain if the child is **B**reathing.
3. Check to see if the heart is beating. (**C** for Cardiopulmonary)

It is recommended that the ITDS be properly trained to administer CPR. A class on CPR usually takes about four hours. Classes are often offered through the American Red Cross, the American Heart Association or in some instances, the County Public Health Department.

**Seizures**

Seizures can be very scary to the child having the seizure and to other children and adults in the environment. Most seizures last only a few minutes and are not life threatening. Febrile seizures occur in very young children and usually do not cause any serious long-term harm. Guidelines for seizures are as follows:

1. If possible, get the child to the hospital or call 911 especially if this is the first time that the child has had a seizure.
2. Place the child on the floor in a safe place and remove any dangerous objects that are close to the child. Place a soft pillow or cloth under the head.
3. Loosen the child's clothing, especially around the neck and head.
4. Do not try to prevent the child from shaking.
5. Do not put any fingers or anything else in the child's mouth.
6. Put the child on his/her side if vomiting to prevent aspiration.
7. Do not give any food or drink.
8. Call the primary medical provider and the family if the child is in the care of someone else.

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**Immunizations**

Immunizations provide infants and toddlers with immunity against disease. It is important to understand the specified times when immunizations are most beneficial. Please refer to the Facts and Myths about Immunizations The CDC publishes the schedule each January. The following is a general guideline of when immunizations are due. The schedule may vary based on location. The primary medical provider will determine when any vaccination is contraindicated for specific conditions.

The ITDS, in concert with the service coordinator, can check on the status of immunizations at the specified times. When should the first set of immunizations be given? What medical conditions require modifications to the schedule of immunizations?

**Dental Care**

Dental health care begins before the first tooth erupts usually between 4 - 7 months, but this varies and can be as late as 10 - 11 months. Usually, the bottom front teeth are the first to emerge. It is recommended that parents can assist dental care early by washing the gums and tongue with a soft damp cloth or gauze after bottle-feeding. This reduces the bacteria left in the mouth. As the teeth erupt, the teeth should also be cleansed with the cloth.

If there are problems with cavities or the gums, the first visit to the pediatric dentist is usually scheduled around the first-year birthday and every six months thereafter, or as prescribed by the dentist. If the teeth and gums are healthy, with good healthy feeding and brushing practices, the first dental visit can be as late as three years old.

An important consideration for dental care is not putting a baby to sleep with a bottle in the mouth. The sugar in the formula will increase bacteria and will wear away the teeth's enamel. The primary or baby teeth are very prone to the acid created by these sugars. If a baby is left with a bottle there is also danger of aspiration and formula entering the Eustachian tubes and causing ear infections. Thus, it is best to feed the baby first and then put the baby to bed.

A consideration during the first year of life is that infants often show discomfort when cutting their teeth. There are tips that the ITDS can share with families on reducing teething discomfort. Please refer to the article on Teething Tots. This will provide helpful information (e.g., cool washcloths and teething rings) that you can provide to parents.
If a tooth is lost prematurely, (e.g., a fall at age 2), the tooth should be wrapped in a clean wet cloth and the pediatric dentist and primary medical provider should be called immediately.

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**Activity #1**
Read the required article Facts and Myths about Immunizations.
What immunizations provide long-term immunity, perhaps for a lifetime, and what immunizations will need to be repeated in a few years? What did you learn?

**Activity #2**
Read the required article Teething Tots. If you have difficulty locating it, go to Kids Health Look in the section on general health on teething tots.
Consider some suggestions the ITDS can give to parents about good dental health for infants and toddlers.

**Activity #3**
Read Common Diagnoses in the NICU If you have difficulty locating it, go to Kids Health Look in the section on "Caring for a Seriously or Chronically Ill Child".
The ITDS may often read medical reports with the team for infants who have been in the NICU. Therefore, it is helpful to become familiar with the terms, including the acronyms that appear in such reports. It is important that the jargon be understood and that there is a common basis of understanding. Many of the diagnoses are referred to by acronyms when communicating with the nurses and doctors on your team. After reading the article, spell out what the acronym stands for and give a definition of the following:

- NEC
- PDA
- TTN
- BPD.

## Infant Toddler Development Training
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**Highlights**
This lesson highlighted nutritional considerations and risks for infants and toddlers. It provided information on specified developmental conditions that represent high nutritional risk. Basic information on acute illnesses, childcare, preventive health such as immunizations, dental care, first aid and CPR, and management of seizures were reviewed.

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Websites

- A Primer on Preemies
- Allergic Reactions
- Bites and Scratches
- Burns
- Children's Hospital and Health System - this website provides information about specific types of endocrine conditions such as diabetes, hypothyroidism, and hyperthyroidism.
- Centers for Disease Control
- Common Diagnoses in the NICU
- CPR
- Cuts
- Down Syndrome - this site provides you with information about Down syndrome.
- Down Syndrome Specialized Growth Charts - this page of the Down syndrome site provides you with access to the specialized growth charts for persons who have Down syndrome.
- Down Syndrome: Health Issues - this site includes the article by Joan E. Medlen, RD, L.D. Looking at metabolism as well as many other articles related to the health issues of persons who have Down syndrome.
- Facts and Myths about Immunizations
- First Aid and Safety
- Florida WIC Program - this site provides information on the Women, Infants, and Children (WIC) program which provides food supplements to low-income mothers and children. Referral forms are also available at this site.

- Food Insecurities - this site includes information related to families that lack food in the United States. It provides one aspect for understanding the environmental risks that may exist for an infant or toddler growing up in a family with food insecurity.
- Fragile X Homepage
- Growth Charts - this site provides information to help the ITDS better understand about plotting growth (anthropometric measures).
- Kids Health - this site provides a listing of numerous articles on children's health. Learners may want to copy the glossary of terms related to the neonatal intensive care unit. The site has information on growth and development, disabilities, assistive technology, pregnancy, newborns, general health, nutrition, and more. This is one learners will want to keep in mind as they visit and interact with families. There are articles for parents, teens, and children. The information is up to date and comprehensive.
- Kid Source
- Looking at Metabolism - this web page provides information about the metabolism of persons who have Down syndrome.
- National Association of Down Syndrome
- Prader Willi Syndrome Association of the USA
- Seizures - this website provides information about the basics of what to do when a child has a seizure.
- Sunburn Fact Sheet
- Teething Tots

# Infant Toddler Development Training
# Module 6, Lesson 3

**Introduction**

This lesson presents basic knowledge related to sensory impairments in infants and toddlers. The information provides a foundation for planning intervention strategies with the team for young children who are blind or visually impaired or hearing impaired. This lesson provides the Infant Toddler Developmental Specialist (ITDS) with information to help the family understand and integrate developmental supports for their child.

**Learning Objectives**

Upon completion of this lesson, you will be able to:

1. Recognize types of sensory impairments, their causes, signs, symptoms, and their effect on the child and family.
2. Identify frequently used medications and adaptive equipment for children with sensory impairments including technological supports.
3. Use diagnostic reasoning to fully participate in the development of an Individualized Family Support Plan (IFSP) and Plan of Care within the context of family needs, priorities, and activities to meet the needs of a child who is blind, visually impaired, deaf, or hard of hearing.
4. Distinguish ways in which a child with sensory impairment affects the dynamics within a family, including the influence on the child.
5. Identify national, state and community resources to assist families in meeting the medical and developmental needs of their infants and toddlers who have sensory impairments.
6. Recognize the Part C/Early Steps eligibility requirements for children who have vision or hearing problems.
7. Adapt the Part C/Early Steps assessment and ongoing monitoring process to include procedures appropriate to the child with sensory impairment.

**Resources**

The following resources are necessary for the completion of this lesson. Learners may wish to access and print a hard copy of the resources prior to beginning the lesson and for future reference. Some resource documents can be found in the Resource Bank. Others are available online.

- Albinism
- All About Strabismus
- Amblyopia
- Cortical Visual Impairment
- Eye Specialists
- Eye Specialist Report
- FDOE Cochlear Implants Memorandum
- FDOE Cochlear Implants Technical Assistance Paper
- How the Eye and Brain Work Together
- Optic Nerve Hypoplasia
- Optic Nerve Atrophy
- Parent Interview Protocol for Child Hearing and Vision Skills
- Part C Criteria Specifying Visual Impairment
- Pediatric Visual Diagnosis Fact Sheet Set
- Retinal Diseases
- Retinopathy of Prematurity
- SHINE Case Examples
- SHINE Communication Building Blocks
- SHINE Early Listening Function Questionnaire
- SHINE Functional Outcomes
- SHINE Index
- SHINE Plan of Care
- SHINE Procedural Safeguards
- Visual Assessment

**Key Words**

Definitions of key words are found in the glossary.

- Albinism
- Amblyopia
- Auditory dyssynchrony
- Cataracts
- Chorioretinitis
- Conductive hearing loss
- Cortical visual impairment
- Glaucoma
- Mixed hearing loss
- Optic nerve atrophy
- Optic nerve hypoplasia
- Retinal diseases
- Retinopathy
- Sensorineural hearing loss
- Strabismus



**Vision and Hearing Overview**

Effective vision and hearing are very important to learning. Most of what typically developing children learn is through these two senses. A loss of functioning in a sensory organ affects the acquisition of developmental skills because the child lacks access to information in his/her environment. If the child is unable to access his/her environment, then active learning is not able to occur at a developmentally appropriate rate. Particularly important are the windows of opportunity for cognitive growth in the first few months to the first few years of life.

It is important to distinguish the sensory impairment from a disability. A disability is the inability to effectively gather information for learning. If interventions can be initiated to assist the infant to gather information for learning, then the sensory impairment can be compensated for, and developmental progress occurs. Therefore, early diagnosis and intervention are especially important for infants and toddlers who have visual or hearing impairments. Sensory impairments can affect incidental learning processes, the bonding experience, the self and body image, motivation, and safety. Learned helplessness and isolation can occur because of the impairment.

# Infant Toddler Development Training
# Module 6, Lesson 3

**Visual Impairments and Blindness**

A visual impairment refers to a functional loss of vision rather than to a disorder of the eye. The eye disorder is what leads to the visual impairment. Any influence that restricts or obstructs vision may affect an infant's window of opportunity to develop normal visual cortical function. The window of opportunity for this development is the first six months of life. Although the sensitive period for the development of visual acuity is during the early years of life, families should not give up on encouraging their child to use whatever vision they have through support of interaction with vision stimulation activities.

Required reading for this lesson includes the Pediatric Visual Diagnosis Fact Sheet from the Blind Babies Foundation Other required reading material to assist the ITDS in learning about common visual diagnoses, their definitions, causes and visual and behavioral characteristics are also found in the Resource Bank. Of major importance to the ITDS are the teaching strategies. These will assist in planning effective interventions. The six common diagnoses and their accompanying information are as follows:

- Cortical Visual Impairment
- Retinopathy of Prematurity
- Optic Nerve Hypoplasia
- Albinism
- Optic Nerve Atrophy
- Retinal Diseases

The ITDS is also required to read a fact sheet about Eye Specialists While reading this information, note the roles and training required of an ophthalmologist, an optometrist, and an optician.

Detailed drawings and definitions are included in the required readings that explain How the Eye and Brain Work Together for visual functioning. Lastly, the learner is required to read

information about the Visual Assessment by the eye care specialist and the important questions that will be asked of parents and caregivers.

# Infant Toddler Development Training
# Module 6, Lesson 3

**Anatomy of the Eye**

The eye is an organ that contains several structures. These include an anterior chamber, lens, and a posterior chamber known as a globe. The globe contains fluid called the vitreous, and the rear or back of the globe is called the retina. The eye operates like a camera allowing light and visual images to be recorded on the retina (like the camera's film).

The anterior chamber contains the focusing part of the eye that focuses light on the retina, which is the seeing sense organ. The muscles of the eye bend the lens to focus the light differently. The iris, or the colored portion of the eye visible to others, is a structure made up of tiny ciliary muscles that open and close the opening of the lens, called the pupil, to control the amount of light that is allowed into the globe. The eyelid also assists the iris in controlling the amount of light. The image that is seen on the eye surface or retina is then transmitted via an electrochemical signal to the visual cortex of the brain. The visual cortex assists in the interpretation of the visual image to link it to the experience. This is called visual perception or perceptual function.

**Visual Impairment**

Visual impairment may be a result of damage to the structure of the eye or even a congenital absence of the eye(s) known as anophthalmia. Visual impairment or blindness can also be caused by damage to other areas of the visual system such as the visual tracts or visual cortex.

Some diseases relating to structural abnormalities of the eye include glaucoma that can affect the anterior chamber of the eye, corneal opacities, cataracts on the lens, and retinal problems such as retinopathy of prematurity.

All eye problems should be referred to an ophthalmologist who is a medical doctor specializing in the care and treatment of diseases and conditions of the eye. The Florida Department of Health is encouraging eye specialists to use the Eye Specialist Report for all children with eye conditions under the age of 3 years. The ITDS can assist in this process by providing a copy of the report to the specialist when he/she knows that a child is being referred for vision testing. The ITDS can also be alert to children who

- Continually rub their eyes.
- Appear sensitive to light.
- Do not reach for toys at the appropriate age.
- Do not track or follow objects.
- Do not blink in response to visual threat such as a hand passed before their face.
- Stare continually at a light.

Children who exhibit some/all the above may need a vision assessment. It is quite possible that they meet the Part C Criteria Specifying Visual Impairment

# Infant Toddler Development Training
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**Prevalence**

The number of young children with visual impairments is relatively small. There are approximately 0.108 % of young children diagnosed with visual impairments. Of these, 3.5 % are unable to perform age-appropriate activities. Children with unilateral blindness have vision in one eye but must adjust their orientation and mobility to accommodate the loss of vision in one eye. This includes the loss of depth perception, as a bilateral visual system is needed for this. Infants and toddlers with severe visual impairment usually have other co-morbidities with other neurological conditions that will require a team approach to plan intervention and support with the family.

**Causes**

Embryological causes of visual impairment can result in a coloboma (a cleft or defect in the normal continuity of a part of the eye) to major malformations or anophthalmia (absence of the eyes). Developmental interruptions in the fetal stage result in minor malformations. Infections during this period can cause cataracts, glaucoma, and/or chorioretinitis.

Vision can be affected by a premature birth. Retinopathy of prematurity or damage to the small blood vessels in the retina can result from the combination of prematurity and exposure to oxygen. The visual system is prone to imbalance during the early years and can be affected by muscle or cortical preference that can result in loss of *visual function*. Problems such as that seen with amblyopia, (an asymmetric loss of vision due to the visual cortex not using the weaker eye as much as the dominant eye for vision), are seen in the first years of life. If amblyopia, sometimes called "lazy eye", is left untreated it can result in some field loss, poor or absent depth perception and possible blindness in the weak eye (Harrell, 1992; Levack, 1994).

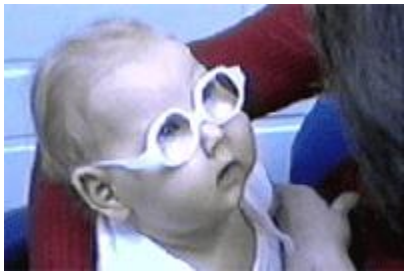
**Issues**

As noted in Lesson One and the opening vignette, families must cope with the loss of the dream of a perfectly developed infant and then plan for major life changes at the same time. When a child cannot see or has less than perfect vision, the family, as well as the child must learn and achieve coping skills. The ITDS should provide support accordingly. In addition, the infant and toddler must learn and achieve coping skills related to his or her developmental level. Plans of Care must always include emotional support as well as community supports that will build the future for the child. This can include services from a local Family Resource Specialist (FRS) through Early Steps and/or counseling services if requested.

**Interventions**

Treatment of eye problems may be medical and/or educational. Examples of medical treatment include medications, corrective lenses, or eye patches. Surgery may also be required. Glaucoma may be treated both medically and surgically. Cataracts require surgical removal. The treatments for strabismus or muscle weakness include the conservative measures of patching the stronger eye and corrective glasses. Sometimes a more aggressive approach includes surgical correction. Retinopathy of prematurity requires

frequent eye examinations. If retinal detachment is a risk, then laser surgery is usually performed.



Educational treatment is a federal entitlement for all persons identified as blind or visually impaired. Services in the State of Florida are provided from birth or upon diagnosis. Infants and toddlers who have visual impairment will usually have slower motor skills attainment. If there is some vision, visual perceptual differences remain. Language differences and an alteration in the development of social skills are also a concern.

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**Terminology**

As young children are assessed for appropriate intervention it is important for the ITDS to understand the terms that families will hear. Services are based on the amount of support a child will need. The National Dissemination Center for Children with Disabilities (NICHCY) provides the following definitions:

- Low vision refers to a severe visual impairment and indicates that the person needs adaptive lenses, adaptations in lighting, large print books or Braille books. This refers to a child whose best corrected vision is lower than 20/70 in the better eye.
- Legally blind means the person has less than 20/200 vision in the better eye or a very limited field of vision.
- Totally blind refers to a person who has no vision and must learn through non-visual instructional methods including the use of Braille readers.

Note: Definitions of blindness and visual impairment vary depending on the discipline or agency providing services. Additional information on terminology, incidence, characteristics, and resources is available through NICHCY.

**Strabismus and Amblyopia**

Strabismus, which is sometimes referred to as crossed eyes, is a condition in which a person cannot align both of their eyes simultaneously due to an imbalance of the eye muscles. One of the eyes may turn in, out, up, or down. The eyes do not work together to focus the image in a binocular fashion. Strabismus also affects depth perception and eye-hand coordination. If untreated, the brain, rather than being confused with two competing visual signals, quits accepting one signal and vision can be permanently affected. More information on this condition can be found by reading All About Strabismus The ITDS should know that this condition differs from amblyopia.

Amblyopia or 'lazy eye' results in reduced vision that is not corrected with glasses or contact lenses and may not be apparent to caregivers. The brain does not fully accept and interpret the image from the amblyopic eye; therefore, it is important that the condition be diagnosed by a thorough eye exam by an eye specialist, especially when the pediatrician suspects the condition during routine well baby checks. Amblyopia is best treated early between the ages of 6 months to 2 years. Additional information can be found through a web resource about amblyopia and Strabismus.

**Consider this scenario.**

The ITDS is likely to assume responsibility as the Primary Service Provider, for children who are referred with strabismus and are patched by the ophthalmologist with poor vision in the un-patched eye. Vision teachers/specialists do not serve this population. It is critical for

parents to receive support in patching the "good eye" so that permanent vision loss will not develop in the "bad eye".

What are strategies the ITDS should follow when working with the young child and the family?

# Infant Toddler Development Training
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**Family Options and Effect on the Family**

If a child has low vision or is blind the family must always be thinking of ways to incorporate vision and tactile stimulation activities into their everyday routines. The ITDS can assist the family to think differently about how they go about their daily activities. For example, the parent may have the child hold an object while the parent talks about it and describes its characteristics. Everything must be touched and described: the toothbrush, the hairbrush, even the toilet.

The parent or caregiver becomes the eyes for the child during these precious early years and as the child grows. The caregiver needs encouragement to use words that describe color, shape, and size and not to veer away from the "seeing" words. The family must ensure that they describe what they are going to do to with their child or what will touch the child prior to taking the action. This is because the child cannot see the approach. Remember, trust is the major developmental task during the first year of life and it is hard to trust if the caregiver approaches in ways that make the child fearful.

The family can be taught additional strategies such as to:

- use a light-colored background on which to place the child's toys.
- make sensory toys from everyday objects such as using beans in a well-sealed potato chip can.
- make textured items.
- use a light box to get objects to show better.

The Florida School for the Deaf and Blind has excellent books and toys for visually impaired children. The American Printing House for the Blind also has good books for parents about visual impairments and blindness. Additional websites can be found in the website section at the end of this lesson that include information on developmental optometry and the use of prisms.

**Referral Requirements for Vision**

Children who are at high risk for eye problems should be evaluated early. The Early Steps Workgroup on Visual Impairments identified high risk populations for follow-up. They include infants who:

- are very premature.
- have family histories of congenital cataracts and/or retinoblastoma.
- have metabolic or genetic diseases that are associated with eye abnormalities.

To qualify for services from the local Early Steps program due to significant sensory impairment in the visual area, the following criteria must be met:

1. Bilateral lack of fix and follow OR an approximate visual acuity of 20/70 or less in the better eye after best possible corrections
2. Constricted peripheral field that could interfere with daily mobility or activities or bilateral central scotoma involving the perimacular area (<20/80)

3. Bilateral Stage III, IV, or V retinopathy of prematurity with evidence of effect on visual performance
4. Bilateral progressive loss of vision which may affect the child's ability to function in his or her natural environments
5. Evidence of Cortical Visual Impairment (CVI)
6. Strabismus that requires patching of the better eye with approximate visual acuity of 20/70 or less in the un-patched eye after best possible correction

(Early Steps Part C Criteria Specifying Visual Impairment Considered to be a "Significant Sensory Impairment", 2004).

*Consider this scenario.*
The ITDS will note that an eye care specialist, who is usually the ophthalmologist, makes the diagnoses of significant vision impairment.

What can the ITDS do to assist the family in the process?

# Infant Toddler Development Training
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**Adapting the Developmental Assessment for the Child with a Visual Impairment**

A parent interview should be conducted as a first step when a vision (or hearing) impairment is suspected. The Parent Interview Protocol for Child Hearing and Vision Skills is available to guide the interview. This document is available in the Resource Bank.
Once it is confirmed that the child has vision impairment, the major consideration for assessment is to have the appropriate team members present. Information from the eye care specialist should be available and presented if the child has a previously diagnosed vision disorder. If a vision problem is known or suspected, it is recommended that a teacher for the visually impaired participate as the primary evaluator of functional skills. Vision protocol requires a full functional vision assessment by a teacher of the visually impaired. A team approach is crucial for infants and toddlers with vision problems. The primary provider and the ophthalmologist should communicate regularly with the family so everyone is operating with the same expectations.

When the child uses glasses or is patched, the team needs to ensure that the glasses and/or eye patch are in place during the assessment. If the child has low vision, a light board and/or a bright background for the presentation of toys and items is recommended. The parents and major caregivers for the child should be present and may be used as the primary presenter of items as they generally know how to ascertain the best responses. The team should observe the child's interactions with people and the environment. Key to the assessment process is knowledge of developmental milestones and how they are affected by decreased vision and reduced interaction with the environment. It is also important to utilize knowledge from the eye care specialist when a diagnosis is provided to plan the intervention strategies.

If the vision diagnosis is known prior to the assessment for intervention planning, the team needs to take appropriate intervention strategies with them to assist the family in planning outcomes for the Individualized Family Support Plan (IFSP). The teaching strategies found in the resources on Blind Babies are excellent as are those found on the strabismus web page (referred to earlier). A teacher of the visually impaired or other vision specialist should be an involved team member in planning the outcomes for the IFSP.

**Testing Instruments**

The developmental assessment must accommodate for the visual impairment when choosing the actual instruments for the assessment. The team needs to read the administration manual of the developmental tests being considered and make appropriate accommodations per the publisher's instructions. Many norm-referenced instruments do not include children with vision problems in the norm sample and therefore would not be appropriate for testing the child. If the child has qualified for Early Steps based on an Eye Specialist Report, then the team would provide only the assessment for intervention planning and would not need to administer a norm-referenced test for eligibility. The team would need to be familiar with the items ahead of time to eliminate or substitute strategies to accommodate any that require vision.

# Infant Toddler Development Training
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**Technological Supports for Vision**

Major assistive devices for infants and toddlers with vision concerns are:

- glasses,
- patching,
- light boxes,
- highly contrasting backgrounds used for the presentation of toys,
- toys that have cause and effect sound makers,
- large cardboard picture books with large print and primary colors, and
- good lighting.

As children get older, they may need access to pre-Braille and Braille material, low vision aides and devices such as monoculars, telescopes, dog guides, etc. The ITDS can assist the family by providing ideas for resources such as those on the web pages at the end of this module. As resources are needed and appropriate, the family should be put in contact with their local Lighthouse for the Blind, the Florida Division of Blind Services, and the local Assistive Technology Educational Network (ATEN). The family should be reminded of these resources as the child approaches transition from Early Steps, particularly if assistive devices will be needed as the child grows and develops.

**Community Services for Vision**

In addition to the resources mentioned above for assistive devices, the ITDS should remember that Plans of Care must always include emotional support as well as community supports that will build the future for the child. This can include other services from the local private vision rehabilitation provider (such as the local "Lighthouse for the Blind"), lending libraries that have lighted switch toys for children with low vision, as well as teachers who specialize in vision services including orientation and mobility.

Camps such as Lions Camp Florida in Lake Wales are sponsored by the Lions Club. Parents can go there with their child to learn strategies that support development.

A family may also want to be put in contact with another family who has a child with visual problems. It may be helpful to call the local Early Steps office and with the family's permission, refer them to a Family Resource Specialist who can assist with this linkage or a linkage to a support group. Support groups are typically provided through a local Lighthouse for the Blind or similar organization.

Although many excellent resources exist, it is important to not overwhelm a family by presenting too much information at one time. It is best to take one to two resources at each visit and discuss them with the family.

# Infant Toddler Development Training
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**Deafness and Hearing Impaired**

As a means of introducing the next major sensory impairment area, the following letter is included. It was written to parents and was shared with Early Steps for use in this portion of the lesson on deafness and hard of hearing. The letter was written by a parent of two children with special needs. It is educational, informative, and sensitive.

*Dear Parents:*
*My husband and I are the proud parents of two incredible children, both with hearing loss. Unfortunately, our state did not have newborn hearing screening when they were born. The similarities between our children are they both use cochlear implants to hear and are siblings. Their paths to this point are remarkably different. My son's hearing loss wasn't identified until he was about 22 months old. He was initially fitted with a hearing aid in his better ear and the second aid 4 months later. At 2 ½, his hearing loss was mild to severe. He began speech therapy and slowly gained language skills. Since our educational backgrounds were not in the medical field, we listened to the medical experts, and followed all their advice.*
*When our daughter was born, we tested her hearing at 3 months on the advice of our ENT. She was born profoundly deaf! After the initial shock wore off and we worked through the emotional turmoil, we felt prepared to help her by whatever means necessary. She began wearing hearing aids at 4 months and started speech therapy at 5 months. I began reading, researching, and meeting other families with deaf children. I discovered that the services my son was receiving were not at all appropriate for a child with hearing loss. We lost critical time and wasted over a year of speech services!*
*Although my son only had a mild to severe loss, which eventually progressed to profound, he experienced a 2-year language gap. His sister who was born with a profound hearing loss, had the advantage of early intervention services, appropriate speech and language services, appropriate amplification, ultimately a cochlear implant at an early age, never had a language gap of more than 12 months! Her language skills developed similarly to those of hearing children. By the age of 4 ½, she closed her language gap. She is fully mainstreamed in the third grade, is an avid reader, plays the piano, dances, takes drama and has an incredible social life for an eight-year-old. Our son is a 6th grader with a sense of humor who plays tennis, flag football, lacrosse, and baseball, is a boy scout, and makes the honor roll at his school.*
*By becoming informed parents of services for the deaf, we searched and found the services that best met the needs of our family. It was a long, long road to where we are today, but worth every minute and experience. Our children are children first, who happen to hear differently than we do.*
*Sincerely,*
*Ann Filloon*

To be prepared for processing this portion of Lesson 3, you are required to read specified materials if you have not already done so. This lesson includes several documents found in the Resource Bank. Specifically, these include resources from the Serving Hearing Impaired Newborns Effectively (SHINE) component of Florida Early Steps.

You will be responsible for the definition of SHINE, the primary philosophies and goals found at SHINE Index. You will also use the Parent Interview Protocol for Child Hearing and Vision Skills which you reviewed in the first part of this lesson. You will need to review the SHINE

Functional Outcomes in order to answer one of the questions related to an activity at the end of the lesson
Please print the following additional documents:

- SHINE Plan of Care
- SHINE Procedural Safeguards
- SHINE Case Examples
- FDOE Cochlear Implants Memorandum
- FDOE Cochlear Implants Technical Assistance Paper

# Infant Toddler Development Training
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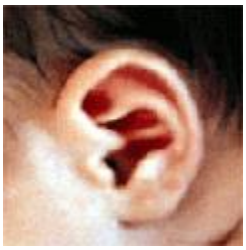
**Anatomy of the Ear**
The ear has three parts: 1) the outer or external ear or pinna and the auditory meatus or ear opening; 2) the middle ear, consisting of the eardrum, the middle ear space, and the three small bones that transmit sound energy from the air to the bones and then to the fluid in the inner ear; and 3) the inner ear that is the actual sensory organ that converts energy of sound to electrical signals that go to the brain via the auditory nerve.

**Symptoms**



Hearing loss is a barrier to perceiving communication that occurs in everyday places. The level of hearing loss, noise in the environment, and distance the child is from meaningful communication or sound all interact to determine the size of the barrier that the hearing loss imposes on development of communication skills. Refer to the SHINE Early Listening Function Questionnaire for more insights into determining the size of a child's "listening bubble".
Hearing thresholds determined through audiological evaluation define the degree of hearing loss. The following paragraphs provide pertinent information on persons with mild to profound hearing loss.

Persons with *mild or unilateral* hearing loss (occurring in only one ear) will have difficulty perceiving speech in a clearly understandable manner at a distance greater than 6 feet. In the presence of noise, they will have inconsistent perception of language and may miss important social cues when no amplification is used.
Persons with a *moderate degree* of hearing loss are unable to hear when conversations occur at typical distances (6 – 8 feet) but will respond to some sounds that occur at close distances when no amplification is used.

Persons with a *severe degree* of hearing loss will not perceive speech sounds unless amplification is used and may not hear all speech sounds depending on their ability to hear across the frequency (pitch) range. Even with amplification, speech sounds may be perceived as substantially quieter than what is experienced by persons with normal hearing. It is important to remember that you need to be relatively close to the person when speaking.
Persons with *profound degrees* of hearing loss will not be able to perceive a substantial portion of the speech signal even when amplification is used. Learning language through hearing alone with a profound hearing loss can be compared to figuring out a picture puzzle with most of the pieces missing. Therefore, visual forms of communication or cochlear implantation is considered as a viable means to augment whatever small amount the child can perceive auditorily.
Ear infection, fluid behind the eardrum or a structural problem with the formation of the outer ear or bones of the middle ear will cause some level of blockage of sound so that it

will not be conducted effectively into the inner ear. Hearing loss caused by these types of blockages is called a *conductive hearing loss*.

**Permanent Loss**

Most of the hearing loss considered 'permanent' is due to missing, deformed, or damaged hair cells in the inner ear. The inner ear is considered the sensory organ of hearing. When a signal created by a sound is conducted into the inner ear, the hair cells bend, and a very small electrical signal is sent up the auditory nerve to the brain. Any problem in hearing that is caused by the hair cells not delivering these signals to the brain is called a *sensorineural hearing loss*.

A person can have a blockage in the outer or middle ear causing a conductive hearing loss that occurs at the same time as they have a problem with the hair cells sending signals to the brain causing a sensorineural hearing loss. In this situation the person is said to have a *mixed hearing loss*.

There are a small number of persons who have normal structures in the outer, middle, and inner ear but who have difficulty processing sound when it reaches the brain. This could be compared to having a radio on but tuned improperly to a radio station so that varying degrees of static are heard along with the music or speech. This is caused by certain nerve cells in the brain not firing in a synchronized manner to bring the sound signal intact to the portion of the brain that can process it for meaning. These persons are said to have auditory dyssynchrony. Persons with auditory dyssynchrony typically receive limited benefit from amplification because hearing aids make sound louder, but they do not assist in 'tuning the radio station' part of the problem. Cochlear implants have resulted in some success in improving the sound processing ability of persons with auditory dyssynchrony. Auditory dyssynchrony can occur in a wide range of impairments and may be present to some degree when sensorineural hearing loss also occurs. In these cases, amplification may provide some degree of benefit.

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**Causes Summarized**

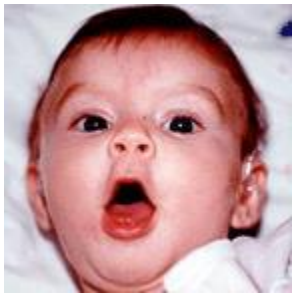
A summary of the causes of hearing impairment is as follows:

1. Lack of anatomy for hearing is one cause of conductive loss. Some syndromes are manifested through the lack of an outer ear or ear opening; however, the internal structure is intact. In cases like this the child will need a bone conduction hearing aid until surgical correction is performed.
2. Conductive loss due to structural abnormalities is common in many syndromes and can be worsened with middle ear infections.
3. Genetic causes are the most common with 1 in 2000 children who have a genetic disorder affected with a sensorineural hearing loss. Genetic hearing loss may have a late onset after birth or can cause congenital hearing loss.
4. Acquired causes include congenital infections or bacterial meningitis in neonatal or infancy periods, high bilirubin levels, exposure to ototoxic drugs, perinatal depression (low Apgar scores), and brain abnormalities that can cause sensorineural hearing loss.
5. Structural causes include malformations that are present from conception. They can also cause sensorineural hearing loss if malformations exist in the inner ear.

**Audiological Evaluation**

It is critical for audiological evaluation to occur by three months of age so that a child with significant hearing loss will be identified and SHINE services can begin. Listening typically begins before birth. Research suggests that the brain development of children with hearing loss will be affected when no auditory stimulation is consistently received. Thus, it is very important for appropriate intervention (hearing aids, SHINE) to be provided prior to six months of age. If consistent auditory stimulation and quality early intervention to develop communication skills is provided after the age of 6 months, a child will learn skills but there may be delays in communication that cannot be effectively habilitated.

By performing a battery of tests, the audiologist can gather information to differentiate between possible sensorineural hearing loss and conductive hearing loss due to the presence of ear infections. During the test, clicks or tones can be presented through earphones (air conduction) and then tones can be sent through a small vibrator placed behind the ear that will direct sound to the inner ear that is embedded in bone (bone conduction). In this way a definitive test to identify permanent hearing loss can be obtained, even if a child is experiencing an ear infection.



When a child is at a developmental age of 5-6 months, they can look around and identify the source of sounds. When a child is 6 months of age or older, the child should be evaluated by an audiologist who will observe the child's reinforced behavioral responses to sound. If the child fails this exam, then the child's ears will be tested with a tympanometer to determine if the cause of the hearing problem could be due to ear infection. An otoacoustic emissions (OAE) test may then be done to determine inner ear/cochlear problems. If the child appears to have hearing difficulty that is not related to ear infection, the audiologist may schedule the child to return for an auditory brainstem response (ABR) test. The ABR is for diagnosing auditory nerve and associative cortex issues of the brain. With this test battery, the audiologist can determine when a child has a hearing loss and the location of the cause of the hearing loss within the auditory system.

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**Issues**

As with vision loss or impairment, hearing impairment and deafness in an infant or toddler brings forth new terms, new ways of planning for the child's future and new issues within a family. One of the most important roles of the ITDS is to assist the child and family in discovering how the child can be integrated within his or her community from the very beginning. The most important resource that can be provided to a family at this time is the information that the SHINE service coordinator and SHINE provider bring. They provide the family with unbiased information on all the methods of communication that can be used with a child who is deaf or hard of hearing. This will help the family make an informed choice regarding how they want to communicate with the child.

**Interventions**
It is important to note that first and foremost, all ear infections need careful follow-up by a primary medical provider. When an infant or toddler fails a hearing screen, the child is re-screened and must have a full hearing evaluation to diagnose the problem if the re-screen is also failed. If a family chooses amplification methods to enhance their child's hearing, the aids need to be fit as soon as possible after the diagnosis is made to promote language acquisition.

If the sensorineural system is intact, but middle ear disease is present, then the infection is treated first, and a follow-up hearing test and tympanogram is recommended. If there is a positive response to treatment within 8 – 12 weeks, then continued follow-up with the primary medical provider is recommended. If there is no response, then myringotomy with tubes is considered.

If the sensorineural system is not functioning properly, but the middle ear is intact, then hearing aids will be considered. The family may then want to pursue an evaluation for cochlear implant(s).

There is a continuum of intervention methods for deafness or hearing impairment. Families need information on all methods to make an informed decision regarding what they want for their child and family. In Florida, all infants who fail their newborn hearing screens are referred to the SHINE program.

Case Examples from SHINE illustrate the outcomes of children who received early intervention services after six months of age and those who received effective intervention prior to six months of age.

*Consider this scenario.*
Baby Timmy who is three months old moved to Florida from a state with no newborn hearing program. The ITDS sees Timmy's mother in a grocery store. The Mother tells the ITDS that she is concerned because Timmy does not respond to her voice.

What guidelines should the ITDS follow when helping a family with an infant who has moved to Florida from another state or who failed a newborn hearing screen in the hospital?

## Infant Toddler Development Training
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**Family Options and Effect on the Family**
Communication modes that the SHINE interventionist discusses with a family include the

- Auditory/Oral Approach
- Auditory/Verbal Approach,
- American Sign Language (ASL),
- Contact Signing or Pidgin Sign Language,
- Cued Speech,
- Finger spelling,
- Manually Coded English.

The following materials are required reading for this lesson:

- SHINE Communication Building Blocks
- FDOE Cochlear Implants Memorandum
- FDOE Cochlear Implants Technical Assistance Paper

It is part of the ITDS' responsibility to know and understand SHINE and to be able to explain the program to parents. It is suggested that you

read SHINE: Language Unlocks Learning. This was written for parents and provides a good summary of what needs to be present for children with hearing loss to have good outcomes.

**Referral Requirements for Hearing**

As discussed earlier, all newborns in Florida are screened for hearing. However, the ITDS should be alert to infants and toddlers who move to Florida from other states and may not have had early screening or diagnosis. If a hearing issue is suspected, the ITDS should refer immediately to the local Early Steps and discuss the need for a hearing screen with the service coordinator. The screening should then be arranged with the family within 45 days of the referral.

**Adapting the Developmental Evaluation and Assessment for Children with Hearing Impairments**

A parent interview should be conducted as a first step when a hearing impairment is suspected. Please refer to the Parent Interview Protocol for Child Hearing and Vision Skills which you reviewed in the vision section of this lesson. This protocol can serve as your guide during the interview.

If a hearing impairment has been diagnosed or is suspected, the evaluation and assessment materials need to be presented in a face-to-face fashion. The only exception would be items where hearing is being assessed. As with any assessment, the team composition is important. A teacher or specialist who works with children who have hearing problems is recommended as a participant and as the primary evaluator. A psychologist and a speech language pathologist are also important members of the team. The audiologist and the primary care provider should be included through actual contact or access to their reports prior to the evaluation and assessment.

If the child has hearing aids these should be in place before any evaluation or assessment is attempted.

## Infant Toddler Development Training
## Module 6, Lesson 3

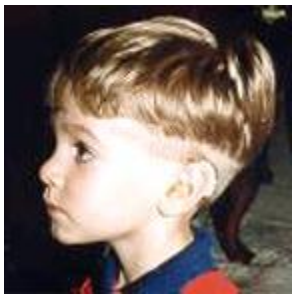
**Technological Supports for Hearing**

The two primary assistive technology aids for infants and toddlers who are deaf or hard of hearing are hearing aids and cochlear implants.

**Hearing Aids**

Hearing aids are amplification instruments that make sounds louder. Hearing aids can be of analog programmable or digital technology. It is an Early Steps policy that infants and toddlers receive hearing aids within one month of diagnosis from an audiologist. Audiologists in Florida are required to refer to Early Steps upon confirmation of a hearing loss that meets Part C criteria. Part C, as payer of last resort, can assist in the coverage of hearing aids per the specifications set forth on page 8 of the SHINE Procedural Safeguards. When working with a child who has hearing aids it is important to ensure that the child is wearing the aids during all waking hours and that the batteries are working. If the child covers his/her ears or pulls the aids out of the ears, it is important for the caregiver to check the function of the hearing aids to be sure they are working properly. It is also important to remember that the audiologist needs to provide continued follow-up to change the ear molds as the child grows, to adjust settings, and to monitor progress. Hearing aids follow up checks are appropriate every 1 – 3 months depending on the child's age.

**Cochlear Implants**



Cochlear implants are electronic devices that are implanted inside the child's cochlea. There is an external device that is a speech processor that is attached to the head at ear level. The device allows electrical signals representing sound to be delivered directly to the auditory nerve. Infants are usually considered for the surgery around 7 - 9 months of age and are implanted shortly after their first birthday. The parents need to do the following daily.

- Ensure that the cochlear implant is working properly by checking to see if the cords are plugged in properly.
- Check to see that the appropriate setting is being used.
- Make sure that batteries are charged and that all pieces appear intact.

Infants and toddlers who use cochlear implants must be followed closely by their audiologist, especially during the first few months, to ensure that the settings are correct, and the child is responding as expected to sound input.

The ITDS should be aware of the effect that static electricity can have on a cochlear device and take the steps recommended in the FDOE Cochlear Implants Technical Assistance Paper such as encouraging the family to use anti-static spray on carpets and clothing. The ITDS can also work with the family to reduce background noises and assist them with strategies for developing listening skills during intervention sessions.
It is important for the ITDS to know that Part C does not pay for cochlear implants.
The FDOE Cochlear Implants Technical Assistance Paper provides a resource list and suggestions on cochlear implants.
Community Services for Hearing Impairment

The SHINE program is the earliest community support for a family. The SHINE service coordinator and SHINE provider have the information on available intervention methods and information on community resources. The SHINE Index provides information on hearing aids insurance, and the hearing aids bank. The Sertoma Clubs are also an excellent community resource for local funding. Their mission is service to the deaf and hard of hearing.

# Infant Toddler Development Training
# Module 6, Lesson 3

**Activity #1**

*Consider this scenario.*

An ITDS is working with Ricky, a healthy two-month-old infant, who has a profound hearing loss in both ears. Ricky's Case Example is found in the SHINE Case Examples. Review samples of outcomes from the SHINE Functional Outcomes resource.
What goals does Ricky's Plan of Care address? What SHINE services are recommended? Consider functional outcomes.

**Activity #2**

*Consider this scenario.*

The ITDS has been chosen by the team to participate in Sandy's first developmental evaluation and assessment. Sandy is 8 months old and smiles when spoken to. Sandy turns her head to sound bilaterally, but the ITDS notices that she does not track objects and shows no response when the ITDS passes her hand in front of Sandy's eyes.

What are the suggestions you will make to the team, including Sandy's parents?

**Activity #3**

*Consider this scenario.*
The ITDS is a member of an assessment team for 20-month-old Danny who was referred to Early Steps by his mother because he didn't seem to be talking. The First Contact information indicates that Danny is an only child and was born in an out-of-state hospital. Danny's mother does not recall if he had a hearing screen. The Mother takes Danny to the Health Department Immunization Clinic for his shots. Danny has not seen a Primary Care Physician since moving to the area four months ago.

What should be the first step in the evaluation/assessment process? What would the Plan of Care include for Danny and his family?

**Lesson 3 Highlights**
This lesson provided the ITDS with an introduction to infants and toddlers who have sensory impairments. Information on the criteria for infants and toddlers to receive vision or hearing services through Early Steps was reviewed. Resource information related to common vision and hearing conditions, assessment, and teaching strategies was provided in the resource materials. It is particularly important to the ITDS to review the SHINE and Blind Babies Foundation materials.

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**Websites**
- The National Dissemination Center for Children with Disabilities (NICHCY)
- American Academy of Pediatrics
- American Foundation for the Blind
- American Printing House for the Blind
- Blind Babies Foundation

- Children's Medical Services
- Cincinnati Children's Hospital
- Deafness in Children Article
- Early Steps Home Page
- FDOE Cochlear Implants Memorandum
- FDOE Cochlear Implants Technical Assistance Paper
- Florida Division of Blind Services
- Florida School for the Deaf and Blind
- Kids Health
- Lions Camp Florida
- Minibibliography on Assistive Technology and Diversity Issues
- Minibibliography on Funding of Assistive Technology for Infants, Toddlers and Young Children with Disabilities
- National Association for Parents of Visually Impaired
- National Federation of the Blind
- NECTAC Clearinghouse
- NIH Eye Diagram
- NIH Eye Photos
- U.S. Preventive Services Task Force on Vision
- Sertoma
- SHINE Communication Building Blocks
- SHINE Early Listening Function Questionnaire
- SHINE Functional Outcomes
- SHINE: Language Unlocks Learning
- SHINE Procedural Safeguards
- Strabismus
- VI Guide

# Infant Toddler Development Training
# Module 6, Lesson 4

**Introduction**

This lesson presents basic knowledge related to neurological and orthopedic conditions in infants and toddlers. The information provides a foundation for planning intervention strategies for young children with neurological or orthopedic conditions. This lesson provides the Infant Toddler Developmental Specialist (ITDS) with information that will be useful in helping the family understand and integrate developmental supports for their child.

**Learning Objectives**

Upon completion of this lesson, you will be able to:

1. Identify types of neurological and orthopedic conditions, their causes, symptoms, and effect on the child and family.
2. Recognize frequently used treatments, medications, and adaptive equipment for children with neurological and orthopedic conditions including use of technological supports.
3. Use diagnostic reasoning to fully participate in the development of an Individualized Family Support Plan (IFSP) and Plan of Care within the context of family needs, priorities, and activities for the child with a neurological or orthopedic condition.
4. Recognize and list how a child with a neurological or orthopedic condition affects the dynamics within a family.
5. Identify appropriate community resources for infants and toddlers who have neurological or orthopedic conditions.

6. Adapt the evaluation and assessment process for the child with neurological or orthopedic conditions.

**Resources**

The following resources are necessary for the completion of this lesson. Learners may wish to access and print a hard copy of the resources prior to beginning the lesson and for future reference. Some resource documents can be found in the Resource Bank. Others are available online.

- Common Childhood Orthopedic Conditions
- NICHCY Cerebral Palsy
- NICHCY Epilepsy
- NICHCY Spina Bifida

**Key Words**

Definitions of key words are found in the glossary.

- Absence Seizures
- Amputee
- Anencephaly
- Becker's MD
- Creatine Kinase
- Dandy - Walker Malformation
- Duchenne's MD
- Dysplasia
- Ehler's Danlos
- Folic Acid
- Hydranencephaly
- Hydrocephalus
- Limb Malformations
- Lissencephaly
- Meningocele
- Mitochondrial Myopathy
- Myelomeningocele
- Neurological Insult
- Orthopedic Condition
- Porencephalic Cysts
- Scoliosis
- Tonic- Clonic
- Ventricular Cysts

# Infant Toddler Development Training
# Module 6, Lesson 4

**Neurological and Orthopedic Conditions Overview**

Incidence and Prevalence of Neurological and Orthopedic Conditions

The incidence of most neurological and orthopedic conditions is relatively rare. For example, Duchenne's muscular dystrophy is estimated to occur in 1: 5600 male children and spinal muscular atrophy, type 1, may occur in 1:12,000 children. Even rarer are some of the bone conditions. As an example, osteopetrosis occurs in approximately 1:200,000 births.

Because the disorders are rare, families sometimes must locate close to medical facilities that specialize in treating the conditions or must travel long distances for treatments or consultations. The ITDS can work with the service coordinator to assist the family in accessing information through the internet that relates to a child's specific condition. Many websites are suggested for the ITDS in this lesson. Information of incidence and prevalence of specific conditions is either included in the discussion of the condition or is referenced on a web page.

**Health Issues and Treatments**
Neurological and orthopedic conditions are some of the most complex conditions that may affect a child. Interventions may require more than two professionals who are best integrated in a multidisciplinary team. Interventions may be medical or therapeutic in nature. Rehabilitative therapies are often needed both pre- and post-surgery to enhance the outcome of function.

The developmental team that works with an infant and toddler who has a neurological or orthopedic condition must maintain contact with the primary medical home and all specialists (e.g., neurologists, orthopedists, therapists). The team may be asked to review requests for adaptive equipment or assistive technology and the ITDS, in conjunction with the team, can prepare for meetings by visiting the library or internet sites such as those listed at the end of this lesson. Because the conditions are rare, the ITDS must be prepared to do the individual research necessary so that supports for development fit into the medical and therapeutic activities of the child's daily routine. Usually there is a need to plan for more frequent breaks during intervention sessions. The ITDS can assist the family by linking them to support networks either through referrals to the Family Resource Specialist or to other parent groups.

## Infant Toddler Development Training
## Module 6, Lesson 4

**Neurological Conditions**
Neurological conditions are those that affect the central and/or peripheral nervous system and other conditions that affect movement and muscles. Neurological conditions include disorders of development, brain malformations, neural tube defects (NTDs), seizures, movement disorders, spinal cord problems, and peripheral nerve problems.

A developmental disorder is a cognitive, communication, adaptive, motor, or social-emotional impairment resulting from a neurological, orthopedic, or other organic problem. Developmental delays, that are sometimes the result of a disorder, are often amenable to "catch-up" over time if an infant or toddler is provided with developmentally appropriate interventions. All children can benefit from early intervention supports and services regardless of the degree of disability or delay.

**Brain Malformations**

Brain malformations are a group of neurological conditions that can affect development in all domains. Brain malformations are described based on the context of normal embryological development. As structures develop in the embryo, various factors such as genetic predisposition will produce defects in the process. These defects will then result in abnormal structures.

The brain and spinal cord begin as a flat disk that folds in upon itself and then shuts like a zipper starting at the end that would be the head or neural fold at the cephalad end. This is the beginning of the brain. This forward or cephalad structure starts to fold in on itself and the structures enlarge and the cells multiply preferentially to form the cerebrum, cerebellum, and brain stem regions of the brain.

There is a cavity formed inside the neural tube that becomes the ventricles and spinal cord. The fluid inside this structure nourishes the internal lining as the circulatory system develops. There is a remarkable magnitude of cellular proliferation and migration during early embryological development so that every organ system in the body develops. The cellular numbers peak at about five months gestation and then begin to gain in size and maturity. The nerve cells (tracts) begin to form protective sheaths called myelin that insulate the nerve tracts and act much like insulation on electrical wires so that short circuits do not occur. The dendrites, small nerve endings that make the connections between the cells, also proliferate until they reach their maximum number postnatally. Dendrites begin to prune themselves at about one year of age as cell functions are differentiated.

At the posterior end of the neural tube, the spinal cord structures develop, and mesenchymal elements envelop them to form muscles. Neurons or nerve cells along the neural tube are also forming myelin sheaths.

Abnormalities (malformations) in brain structure have their origin in these early processes of embryological formation with the most significant problems resulting from interruptions or deviations from the typical processes somewhere in the second to fourth month of gestation.

**Lissencephaly** or "smooth brain" is one of the malformations. It is part of many different syndromes and at least one of these is caused by a gene defect. This results in a lack of convolutions or folds on the brain. *Agyria* is complete absence of folds.
**Pachygyria** is an abnormality of few, unusually broad gyri and is associated with an abnormally thick cortical plate. It is closely related to lissencephaly.
These defects are caused from migrational defects where the cells do not get to their designated places. If these defects occur in only a small portion of the brain there may be no noticeable problems, but if the defect covers a large portion of the brain there are often major developmental issues.

Significant brain malformations can be seen on imaging studies. Many other disorders of brain development may not be seen by standard imaging studies. However, they may be present and detected as they become manifest by their symptoms which often include moderate to severe retardation.

Besides these defects which can be detected with imaging studies (such as lissencephaly and pachygyria), other defects such as anencephaly (absence of most of the brain), *Dandy-Walker malformations* (agenesis of the 4th ventricle structures), *absence of the corpus callosum*, certain types of *Arnold-Chiari malformations, porencephalic cysts* occurring in the lateral ventricles, and *hydrocephalus* (water on the brain) can also be seen with imaging

techniques. Cerebellar malformations, such as cysts, and abnormalities of the cerebellum, such as Arnold-Chiari, may also involve the brain stem. They may cause hydrocephalus, due to the obstruction of the spinal fluid circulating system, often at the level of the third and fourth ventricles of the brain.

# Infant Toddler Development Training
# Module 6, Lesson 4

**Neural Tube Defects (NTDs)**
Neural tube defects or spina bifida are another of the neurological conditions.

Please refer to NICHCY Spina Bifida for required reading before going further in this section. For very specific information about spina bifida and hydrocephalus, including treatments and supports, you may visit the following two websites:

- Hydrocephalus Association
- Association for Spina Bifida and Hydrocephalus

Neural tube defects (NTDs) are defects of the spine that occur because of the neural tube failing to close. This is called spina bifida or myelomeningocele. A spina bifida may be an open defect or a closed (occulta) defect. In spina bifida occulta the spinal cord is not open to the outside. It is estimated that 5 - 10% of the population has a spina bifida occulta that is undetected and causes no problems.

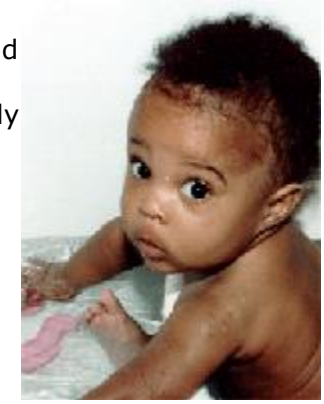
Open defects are referred to as spina bifida cystica (cyst or sac like). Open defects mean that part of the tissues or the spinal cord itself may be outside of the spinal column. The defect is exposed to the outside world and the risk of infection and complications is great unless treated shortly after birth. The treatment is surgical intervention to close the opening.

There are two types of spina bifida cystica: meningocele and myelomeningocele or meningomyelocele. Meningocele is the least common type and results in very little disability. The sac in a meningocele contains tissues but does not contain nerves or spinal cord making the surgical repair relatively simple.

The second type of spina bifida cystica, myelomeningocele or meningomyelocele, may cause significant disability because the spinal cord itself is outside the spinal column. It is so named as the meninges or the protective covering of the brain and spinal cord, as well as nerves and part of the spinal cord, are outside the body. There is risk of infection and increased intra-cranial pressure. The defect results in movement disorders and bowel and bladder involvement.

These neural tube defects occur from failure of closure of the neural plate to become a closed tube. The open defect allows the spinal cord to be in direct contact with amniotic fluid and eventually to the outside world after delivery. The defect can be isolated to the spinal cord, or it can involve bony malformations.

Neural tube defects may be a result of chromosomal deletions and/or a deficiency of folic acid in the mother's diet. Therefore, women, prior to and during child-bearing years, are encouraged to eat foods such as bread fortified with folic acid, green leafy vegetables, and liver.



Prognosis in spina bifida is associated with the location of the defect. If the defect is low around the S-2 or S-3 of the sacral spine, the child is usually able to walk without adaptive equipment. If the defect occurs around the L-4 or L-5 of the lumbar spine, the child will usually be able to walk with crutches or support. If the defect is higher around L-1 or L-2, the child will generally need a wheelchair for mobility. Many specialists are involved in the life of the child and family including orthopedic doctors, therapists, neurologists, urologists, and special educators.

The higher the lesion or defect, the more likely is the associated presence of an Arnold-Chiari malformation. An Arnold-Chiari Malformation is a congenital deformity at the base of the brain in which cerebellar tissue extends into the fourth ventricle of the brain. It is often associated with spina bifida. If an Arnold-Chiari malformation is present, then seizures, learning disabilities, and shunt issues are associated concerns.

Higher lumbar defects are also associated with scoliosis or curvatures of the spine such as kyphosis and lordosis. *Kyphosis* is a posterior curvature of the thoracic spine usually the result of a disease (lung disease), or a congenital problem. *Lordosis* is a curvature or bending backward at the lower spine. These are generally accompanied by hip/knee/foot problems, skin problems from immobility, and bowel and bladder incontinence. Seizures, learning disabilities, and shunt issues may also be associated with higher lumbar defects. Lower lumbar defects do not have the associated scoliosis and hip problems that are associated with the higher lumbar defects. The defects are generally only associated with bowel and bladder problems.

**Role of the ITDS**
If hydrocephalus is present, the child may require a shunt to drain the cerebral spinal fluid. The ITDS can be alert to infections in children with shunts by noting changes in behavior such as irritability, changes in somnolence, or loss of developmental skills. Many persons who have shunts are allergic to latex.

Think and reflect on what the ITDS should do with a child who has a shunt and may be allergic to latex. What about the childcare provider?

What should the ITDS remember about the cognition of children with Spina Bifida?

Consider some ideas of how the ITDS can help the family whose child has Spina Bifida.

# Infant Toddler Development Training
# Module 6, Lesson 4

**Overview of Seizures**
A seizure is an involuntary spasm of a muscle or muscles. A seizure can be as mild as a tic or an eye blink to tonic and clonic jerking of muscles and a loss of consciousness. Seizures can be an isolated neurological condition or seizures can be an associated symptom of another neurological condition.

Please refer to NICHCY Epilepsy for a required reading before going further in this section. One seizure does not equate to a seizure disorder. A single seizure may be the result of a high fever, an acute central nervous system infection, or a traumatic injury including a concussion. However, all seizures need to be evaluated for cause.

If a child has repetitive seizures, it is called epilepsy. Epilepsy is a chronic neurological condition characterized by recurrent seizures that may occur with or without other brain

abnormalities. Several factors may influence seizure activity including changes in growth, metabolism, and sleep. Seizures may be brief or continuous and require emergency intervention if they do not stop.

**Causes of Seizures**

Seizures are a sign of brain dysfunction and have a variety of causes including hypoglycemia (low blood sugar), hyponatremia (low sodium), hypocalcemia (low calcium), infections, trauma, and malformations of the structures of the brain. Seizures originate with abnormal hyper-synchronous electrical discharges from the cortical neuronal network in the brain. These electrical discharges lead to an interruption in the usual brain generated electrical signals that result in an abrupt change in a person's behavior.

Seizures that are due to perinatal asphyxia/hypoxia do not usually begin right at birth but, often are manifest within 24 to 48 hours following the birth. Seizures in newborns are often not full-blown and the symptoms can be very subtle. These seizures in newborns tend to be generalized but, may be partially complex or focal in distribution.

**Classifications of Seizures**

Classifications of seizures are usually based on the clinical symptomatology and on electro-encephalogram (EEG) reports. Manifestations of seizures include altered consciousness, and prominent motor manifestations. Seizures with primarily altered consciousness include generalized seizures, absence seizures, and simple and partial complex seizures. Seizures with prominent motor manifestations include myoclonic and atonic seizures, tonic – clonic seizures, status seizures, and febrile seizures.

**Risks and Diagnosis**

Seizure disorders tend to be highest in children who have a positive family history of seizures. For infants and young children, a common trigger is an illness often accompanied by fever. Trauma can also precipitate a seizure.

Seizures are diagnosed by measuring brain wave patterns using an EEG. The best time to confirm a diagnosis is to run an EEG when the child is having the seizure. Brain imaging can also assist in the diagnosis of pathology such as brain malformations but are not used to diagnose a seizure.

**Mimics of Seizures**

There are conditions that mimic seizures. These include sleep disorders such as *parasomnias,* sleep *myoclonus* (irregular and involuntary contractures of the muscles that occur while sleeping), and *dystonias* (abnormal muscle tone) that may be hypertonia, hypotonia, or mixed tone.

A *syncope* syndrome may also mimic a seizure. Syncope is a brief loss of consciousness that is caused by a sudden drop in blood pressure or a failure of the regular rhythm of the heart that results in a lack of oxygen to the cerebrum.

A migraine headache may also mimic a seizure. Sometimes young children will hold their breath and may even pass out. This may also include a seizure.

Information about the basic first aid for Seizures was referenced in lesson 2 of this module.

## Infant Toddler Development Training
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**Movement Disorders**

Read NICHCY Cerebral Palsy before going further in this lesson. More comprehensive information can be obtained through the United Cerebral Palsy Organization. This details causes, prevalence, classifications, treatments, and supports of cerebral palsy. Information in Spanish is also available.

The most identified movement disorder is cerebral palsy. Cerebral palsy is a condition that affects body movement and coordination and is not a disease. Cerebral refers to the "brain" and palsy refers to "weakness". Cerebral palsy is defined as a significant motor impairment manifesting itself as abnormalities of posture and tone. It is due to brain damage that created the abnormalities in function. The damage once done does not progress. The damage may have occurred prenatally (before birth), perinatally (during birth) or in the postnatal period. Cerebral palsy may also result from a traumatic injury. Cerebral palsy is defined by weakness, spasticity and/or hypotonia. Associated issues may include global delays, mental retardation, and oral motor dysfunction. It is often difficult to identify isolated motor involvement versus global developmental delay in younger children.

There are two types of cerebral palsy. The first involves the place where the brain injury occurs and consists of two kinds: *pyramidal* (involving neurons within the cerebral cortex) and *extrapyramidal* (involving areas outside the cerebral cortex). The terms spastic or cortical refer to pyramidal lesions, and the terms *athetoid, sub-cortical or ataxic, or hypotonic* refer to extrapyramidal and are interchangeable. Both types can be mixed in patients. Spastic cerebral palsy means that the child has stiffness or contractures of the muscles making movement difficult and does not go away during sleep. This is the main type of cerebral palsy affecting 70 – 80 % of persons who have the condition. Athetoid cerebral palsy refers to uncontrolled or writhing movements. Ataxic cerebral palsy is when the condition affects balance and perception.

A second type refers to the distribution of involvement. So, the terms monoparesis, diparesis, triparesis, and quadriparesis refer to how many limbs are involved. The term – *plegia* is often incorrect and the term – *paresis* should be substituted. Rarely is a child completely devoid of movement which is what plegia implies.

Medical treatments for cerebral palsy sometimes include Botox injections. Surgical treatments to assist in the relief of contractures in extreme cases are occasionally recommended.

Intervention Role of the ITDS

The ITDS may be working with neurologists and therapists as well as the primary medical provider when on the team for an infant and toddler with cerebral palsy. There are many therapeutic regimens and the ITDS is encouraged to read about various treatments. It is best practice to research specific treatments each team discusses to ensure that the efficacy of treatment is backed with scientific data.

Consider how the ITDS should provide information to families on treatment options. What should the ITDS do in this regard?

Consider what role the ITDS may have regarding equipment use for children with movement disorders. How would he/she be involved?

Reflect on how the ITDS could be instrumental in ensuring that the child and family have opportunities to infuse interventions into everyday activities, routines, and places. Can you come up with some suggestions?

# Infant Toddler Development Training
# Module 6, Lesson 4

**Spinal Cord Problems**

There are neurological conditions that directly affect the spinal cord. These include *Syrinx, Disc Disease, and Transverse Myelitis*.

A syrinx is associated with an Arnold-Chiari malformation in 90% of the cases. A syrinx is a fluid-filled cavity that develops in the spinal cord. It is sometimes called a syringomyelia. Thirty percent of tumors in the spine result in a syrinx. They create pressures on the cord and reduce or eliminate the sensation of pain and changes in temperature. Most commonly a syrinx occurs in the neck area, however they may also extend into the brain. This requires draining the defect and it can reoccur and need to be re-drained. Magnetic resonance imaging (MRI) is used to diagnose and follow the condition. The ITDS can assist the family to carefully check water and food temperatures and alert the family to take precautions around fire for children with this condition.

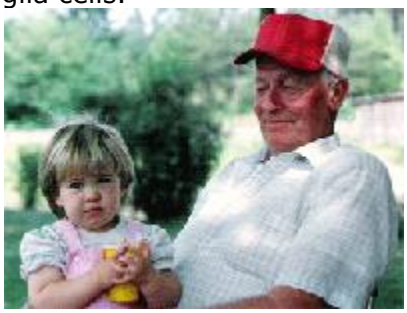
Disc disease (literally, a wearing away of a disc pad between the spinal bones) is compression of a disc with resulting pressure on nerves and tissue. It may be associated with one of the orthopedic conditions, but also can damage nerves. It is unusual in children unless present from birth.

Transverse myelitis is an inflammatory process involving the spinal cord's gray and white matter that may be associated with spina bifida and other neurological disorders.

**Tumors**

Tumors are uncontrolled cellular growth that creates abnormal masses. There are two types: *Primary and Secondary*. A primary tumor is in the organ where the overgrowth of cellular tissue originated. A secondary tumor is made of cells that originated in another organ and spread (metastasized) to other locations. Most brain tumors in childhood are primary tumors that originate in nerve cells of the brain called glia cells.

Another way to consider tumors is that some are benign, and some are malignant. A benign tumor grows slowly and doesn't spread to other locations. A malignant tumor spreads quickly to other areas of the body. Malignant tumors are referred to as cancer.



**Clinical Signs**

Some of the symptoms of brain tumors in early childhood include nausea and vomiting, headaches, changes in growth, cognition, and irritability. A brain tumor may cause other issues such as diabetes or changes in metabolism.

Diagnostic methods of confirming a brain tumor include an electroencephalogram (EEG), a computerized tomography (CT) scan, or MRI scan. After the diagnosis is made, treatment options include radiation therapy to shrink the tumor and chemotherapy. Daily care of the child undergoing treatment includes control of the nausea and vomiting and reassurance about the loss of weight and of hair.

There may be a need for short term occupational, physical, or speech therapy as treatment will destroy some of the normal brain cells. Effects of the tumor and/or of the treatment may be short- or long-term learning disabilities. A neurologist and/or oncologist usually

follow the child to ensure that there is not a recurrence of the tumor. The primary role of the ITDS will be supporting the family in locating information and other community resources.

**Peripheral Nerve Problems**
There are several neurological conditions related to peripheral nerve problems that may be manifest in infants and toddlers. Most of these conditions are rare and affect many peripheral nerves. Some, however, affect isolated nerves such as a facial nerve palsy or an Erb's palsy affecting an arm and are frequently due to birth trauma.

## Infant Toddler Development Training
## Module 6, Lesson 4

**Muscle Diseases also known as Muscular Dystrophies**
Some neurological disorders are related specifically to the atrophy or wasting away of the muscles due to processes in the muscles only. This is called muscular dystrophy. The two most common muscular dystrophies are *Becker's* and *Duchenne's*. The onset of Becker's type is later, and the progression is slower than in Duchenne's. In both types, because of its x-linked inheritance, the incidence occurs only in males although the carrier is female. Usually, Duchenne's is diagnosed in boys ages 3 to 7 years. In a limited number of cases Duchenne's has been diagnosed in the toddler years. As a rule, the earlier the diagnosis, the more severe and rapid the progression of the disease. Many boys who have Duchenne's are in wheelchairs by the age of ten years. Becker's, with its slower onset, is not usually diagnosed until around the age of 10 years.
The symptoms of muscular dystrophies include progressive and proximal muscle degeneration, muscle wasting, cardiomyopathy, and enlarged calves. The muscle wasting may result in scoliosis, congestive heart failure, and loss of ambulation. Treating with glucocorticosteroids sometimes prolongs the ability to ambulate.

Once the child is diagnosed, the family generally needs extensive support in dealing with grief. Mothers particularly may feel responsible, because they are carriers for the disorder, yet females themselves are protected because they have a normal "X" chromosome.

Consider how the ITDS may assist the family whose child has muscular dystrophy. What can you suggest?

**Mitochondrial Myopathies (MITO or MM)**
Mitochondrial myopathies are due to abnormal functioning of the mitochondria (energy producing cell structures) that results in muscle weakness. These myopathies have associated complications that can include seizures, sensory issues, diabetes, migraines, and cardiac disease.

Mitochondrial myopathies also referred to as MITO or MM may cause several problems in children. Problems include gastrointestinal problems that can result in inadequate nutrition. Other issues include epilepsy, drooping eyelids (ptosis) that can interfere with visual function, fatigue, and poor balance. Muscle weakness can result in respiratory problems and the child may require a ventilator to breathe. Some of the more common (though extremely rare) mitochondrial myopathies are Kearns-Sayre syndrome, Leigh's syndrome, mitochondrial deletion syndrome (MDS), and mitochondrial encephalopathy.

As with all muscular dystrophies the main goals on an intervention plan would be to ensure

a. full integration into the community
b. maximization of functional capacities
c. maintaining and prolonging function and locomotion
d. decreasing or preventing a deformity

Go to Muscular Dystrophy Association of the USA. This is an excellent website that provides information about various muscular dystrophies including characteristics, age of onset, progression, treatments, teacher tips, and specialists who may become involved. The site includes the mitochondrial myopathies. Information can be found on the site both in English and Spanish. Specific pages that address the mitochondrial myopathies, issues and treatments are MDA USA Mitochondrial Myopathy and MDA USA Publication on MM .

**Anterior Horn Cell**

Peripheral nerves originate in anterior horn cells that control movement. When they degenerate, there are motor deficits; yet the sensory functions may still be intact. One of the most famous of the anterior horn cell degenerative conditions is Amyotrophic Lateral Sclerosis (ALS also known as Lou Gehrig's Disease). The condition usually affects individuals much later in life; however, infants and toddlers may have anterior horn cell damage related to a myelomeningocele that will affect their motor abilities. Spinal muscular atrophy or Werdnig-Hoffmann Disease also involves anterior horn cell dysfunction. It is a congenital neuromuscular disorder associated with progressive muscular atrophy, weakness, and loss of motor skills. Spinal muscular atrophy types 1 and 2 are autosomal recessive genetic conditions. Both are fatal conditions; although with good medical treatment and care persons who have type 2 can survive into the third decade of life.

Polio is a viral infection of the spinal cord that affects the anterior horn cells and causes an asymmetrical ascending paralysis. Polio, once common, is now almost eradicated worldwide due to vaccination.

**Motor End Plate**

The motor end plate of a nerve cell sends signals from the neuron to the associated skeletal muscle. Motor end plate diseases occur when there is a failure of motor nerve impulses to cross to the muscle end plate at the neuromuscular junction. It includes such diseases as infantile botulism, toxic-metabolic disturbances, and Myasthenia Gravis.

Myasthenia Gravis is characterized by progressive fatigue and weakening of the skeletal muscles caused by impaired transmission of nerve impulses caused by an autoimmune attack on nerve cells called acetylcholine receptors. The condition is very rare in children, although it can occur. The condition may show improvement with a medicine called mestinon or immune therapy as it is an autoimmune disorder.

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**Orthopedic Conditions and Associated Factors**

Common Childhood Orthopedic Conditions

An orthopedic condition is a condition that affects the skeletal system. Examples include diseases of the muscles such as those described in Part 1 of this lesson, intrinsic disorders of the bone, joint problems, and limb problems.

The ITDS should be aware that there are several common orthopedic conditions that can affect any infant and toddler and do not result in developmental disability or delay. However, if necessary, treatment is neglected, a child may have trouble in motor development. Some of the most common conditions include *Flatfeet, Toe-Walking, Pigeon Toes, Bowlegs, and Knock-knees*.

**Flatfeet** occur in approximately twenty percent of the population and usually do not create a problem for the child. It is considered a normal variation of human development.

**Toe walking** is common in young toddlers and is only a concern if it persists past the age of two and in a prolonged fashion rather than as an intermittent occurrence. If a continuous pattern of toe walking continues past the age of two years, the toddler should be evaluated to determine if the child has cerebral palsy

**Pigeon toes** are when the toes turn inward. Pigeon toes are also considered a normal condition of infants and toddlers who are learning to walk.

**Bowed legs** of an infant or toddler should be evaluated by a medical professional to determine if the child has rickets or if the tendency is one that will improve with time. Rickets is caused when the child does not get enough vitamin D. It is easily treated. Severe bowlegs may be an indicator of a more severe problem and must be evaluated by the primary medical provider who may suggest a consult with an orthopedic specialist.

**Knock-knees** occur as children grow and the alignment of their body changes. The primary medical provider should follow the condition and refer to a specialist if the condition is severe.

To learn more about the common conditions described above, read information in the document, Common Childhood Orthopedic Conditions This is a required reading.

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**Muscle Diseases that Affect the Skeletal System**

Muscle diseases include muscular dystrophies such as Duchenne and Becker's previously described as well as the mitochondrial myopathies.

**Intrinsic Disorders of Bone**

Intrinsic disorders of the bones that result in brittle bones include osteopetrosis and osteogenesis imperfecta (OI). Other causes of brittle bones are osteopenia of prematurity, medications taken for the control of seizures, and brittle bones that occur in children who are non-ambulatory. Non-ambulatory children who might have brittle bones include some who have cerebral palsy and neural tube defects.

- **Osteopetrosis** is a genetic disorder. In this disorder, there is a build-up of bony tissue that results in death.
- **Achondroplasia** is a genetic disorder that results in extremely short stature, large head, and short limbs. Cognition is usually not affected however, there are usually delays in motor skills. There are also medical risks for apnea, compressed spinal cord, and sometimes hydrocephalus. Professionals who often attend to this condition include a primary pediatrician, developmental pediatrician, and a pediatric nutritionist.
- **Osteogenesis Imperfecta (OI)** is a genetic disorder resulting in very brittle bones whereby even normal activity and pressure can result in breaks. Osteogenesis imperfecta varies from mild to very severe. In extreme cases, a child may have

several bone breaks while still in utero. A cough or rolling over in bed may cause a break. In these severe cases, a family may need to put special padding on the floors of their home, eliminate or pad metal doorjambs, create roll under counters, and make numerous other modifications to protect their child. The condition is a result of either too much or too little collagen (elastic substance) in the bones. The condition may be treated with medications such as bisphosphonates and forteo to make the bones stronger. The insertion of surgical rods is another treatment that is used occasionally for this condition. To learn more, you may explore information through the Osteogenesis Imperfecta Foundation

- **Osteopenia**: This orthopedic problem is a loss of bony tissues. The condition may result from non-ambulation in children who have cerebral palsy or neural tube defects. Osteopenia occurs in very premature infants because of nutritional problems.

Consider how the ITDS could work with a child with OI or one of the other rare conditions described above. Do you have some suggestions?

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**Joint Problems**

Another type of orthopedic condition is joint problems. Joint problems in toddlers include arthritis, and those acquired through maladaptive postures and movements associated with cerebral palsy, arthrogryposis, developmental hip dysplasia, and joint laxity.

- **Arthritis** is an inflammatory disease of joints.
- **Arthrogryposis** is a non-progressive disorder that is manifest with symptoms of joint contractures that begin prenatally with resulting muscle weakness around the involved joints.
- **Developmental Hip Dysplasia** is very amenable to treatment if detected early. In layman's terms, developmental hip dysplasia is a condition where the hip bones slip in and out of their sockets. This can lead to severe orthopedic problems if not detected. Newborns are screened for the condition by physical examination, but diagnosis is often not made until later in infancy because it would be inappropriate to routinely screen newborns with MRIs and other methods that might be used with an older child. The ITDS can learn more about the early detection of developmental dysplasia of the hip and the difficulty that the primary medical provider has in making this diagnosis. This practice guideline can be found at AAP Practice Guideline on Developmental Dysplasia of the Hip
- **Joint Laxity** is a looseness of the joints sometimes associated with certain syndromes such as Ehlers-Danlos syndrome. Ehlers-Danlos is a rare defect of the connective tissue that may be found in skin, muscles, joints, and ligaments. The main characteristics of the syndrome are loose joints, hyperextensibility, dislocations, and fragile skin. There are ten distinct forms of the syndrome dependent on signs and symptoms (Jones, 1997). The disorder is rare, occurring in 1:10,000 individuals. Information on the condition can be found at Ehlers-Danlos National Foundation Joint laxity may also be associated with other syndromes such as Down syndrome.

Consider how the ITDS can assist the team, including the family, when working with a child with joint problems? Do you have some ideas?

Are there resources for rare neurological and orthopedic conditions that would be helpful to the ITDS and families they serve?

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**Limb Problems**

Limb malformations and amputated limbs are other types of orthopedic conditions seen in infants and toddlers. A limb malformation is defined as a deformity of a limb and includes webbed fingers or toes. The malformation may be as small as a misshaped thumb or missing digits (fingers or toes) or a loss or partial loss of an arm or leg. Infants and toddlers who are born with malformed limbs often have other associated conditions, particularly if they have certain rare syndromes. A team approach to treatment is needed. The child will see an orthopedist and specialists who make orthotic or prosthetic devices. An orthotic device is a device that increases the child's independent functioning. A prosthetic device (prosthesis) is an artificial limb. Please note that the child with an uncomplicated malformation may not qualify for Early Steps.

**Amputees**

Some infants and toddlers may need surgical removal of all or part of a limb. This is called amputation and the child is referred to as an amputee. The child will need support of their medical team that may include a child life specialist. The child life specialist is a person who has special training and who works in the hospital to help children cope during hospitalizations and stressful events. Children need support to adapt to a body image that is changed. The family also will need support to make decisions regarding the amputation and to cope with feelings about the altered appearance of their child.

Medline Plus Amputees is a resource that can be accessed for information about limb loss. The website has peer contact for parents of children who are congenital amputees and contains information on summer camps for children as they get older.
Consider how the ITDS can help families who are coping with the altered appearance of their child due to limb loss? Can you give at least one idea?

**Traumatic Brain Injury**

A traumatic brain injury is a trauma that is sufficient to result in a change in level of consciousness and /or anatomical abnormality. Both the neurological and the orthopedic systems may be affected dependent on the severity of the trauma. Approximately one in twenty-five children each year will have a head injury, including scalp lacerations. One in 500 children will have a significant traumatic brain injury that results in altered consciousness. Children, birth to 5 years of age, represent a high-risk group because of their continuing motor and cognitive development.

**A brain trauma may be mild, moderate, or severe.**

- **Mild trauma** - an example of a mild head injury is a concussion. There is usually a brief loss of consciousness, confusion, or amnesia. Concrete neurological findings are generally not present, and the effects of the injury are temporary. There may be a behavior change, irritability, and change in cognitive functioning, and an increase in learning problems after a concussion, but these are relatively brief.

- **Moderate to severe trauma** - this may result in coma. A coma usually is a sign of diffuse axonal (nerve) injury, but the coma may also be the result of a focal injury. Coma is evaluated on scales that rate eye, motor, and verbal responses.

Head injury is often local in effect, but this depends on the nature of the forces that create the injury. Inertial forces tend to cause more diffuse damage and more internal injury. Forces such as those that may occur in high-speed automobile accidents may also cause spinal cord injury, deep organ involvement, and orthopedic problems.

# Infant Toddler Development Training
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**Child Abuse and Neglect: Reporting Requirements**

Child abuse and neglect is behavior outside the norm of conduct by a caregiver and entails a substantial risk of causing physical or emotional harm to a child, including traumatic brain injury. Child abuse and/or neglect can lead to a physical or emotional disability. The ITDS needs to know the signs and symptoms of child abuse and neglect in order that appropriate reporting is made, and interventions instituted.

There are three recognized types of abuse: physical, sexual, and emotional. There are four types of neglect: physical, medical, educational, and emotional. The incidence of abuse and neglect by report is an overall rate of 23/1000 children: physical abuse, 3 – 6/1000 children; sexual, 3/1000 children, and neglect, 13/1000 children. The rate is increased 5 – 10 times when parents are surveyed retrospectively.

**Physical abuse** in infants and toddlers may be detected by the ITDS if the child has multiple unexplained bruises, scars, cuts, welts, or burns. However, sometimes the physical signs are not evident. In these cases, withdrawn or aggressive behaviors often become the first clue to the abuse.

**Shaken Baby Syndrome** is one of the most common forms of physical abuse. It is a form of head trauma in an infant or young toddler that can result in death or permanent disability. This occurs when a parent or other caregiver shakes the baby so hard that the head moves in a whiplash fashion. Often this is done to quiet the baby. Most parents and caregivers who shake their babies do not know that the shaking action causes bleeding and swelling of the brain. The National Center on Shaken Baby Syndrome is a source of information for families, childcare providers, and other professionals about this condition. The National Shaken Baby Syndrome Campaign is focusing attention on this problem. The ITDS can assist this educational effort by providing information to caregivers about the effects of Shaken Baby Syndrome. This may save an infant's life or prevent a disability.

**Sexual abuse** may occur with infants and toddlers. If the ITDS suspects that a child is being exposed to sexual contact, activity, or behavior that is inappropriate for the child's age, she/he must report this to child protective services or the police. Prevent Child Abuse America has a fact sheet which the ITDS can share with parents and other caregivers on Sexual Abuse of Children .

**Emotional or verbal abuse** is hard to discern at an early age. Sometimes the behaviors of the child and the caregivers lend clues to the emotional abuse. A very young child may be overly passive or overly aggressive. The child may appear depressed or withdrawn. The infant or toddler may be hard to engage or may engage inappropriately with strangers; yet show little connection to their primary caregivers. The caregiver's behavior can include shouting, belittling comments to the child, lack of affection toward the child, and rejection of the child's attempts to engage. Because there are no physical signs of the abuse, emotional abuse may go untreated. If the ITDS suspects emotional abuse, the team may want to consider involving an early intervention mental health counselor or social worker as the primary provider for the child and family.

**Physical Neglect**: Child neglect may result in delays of physical, communicative, and cognitive development. Signs of physical neglect include malnutrition; repeated pica (eating of dirt, paint, clay, etc.), physical fatigue, and poor hygiene.

**Medical Neglect**: Signs of medical neglect include the persistence of treatable medical conditions such as failure to have a child immunized or provide dental care. Medical neglect can include the absence of necessary prostheses, such as eyeglasses and hearing aids, or protective gear such as helmets.

**Educational Neglect**: Educational neglect is the failure of caregivers to ensure appropriate instructional programs and schooling for a child.

**Emotional Neglect**: Emotional neglect occurs when the caregiver is not able to attend to a child's needs for love, acceptance, and esteem building. The caregiver may be unable to bond with an infant for various reasons including her/his own emotional issues. If the primary caregiver is unavailable emotionally, the team may need to explore other options to support the emotional needs of the child. The team may consider means for providing another adult caregiver in the child's life to support the child's emotional needs. The team may also want to consider a mental health counselor or licensed clinical social worker to work with the primary caregiver and the child as a dyad. (A dyad is two people who are treated together as a unit such as a caregiver and a child). The ITDS should be aware that contributors to child neglect include parental depression, social isolation, intellectual impairments, financial problems, substance abuse, limited education, unemployment, marital stress, and mental illness. Child factors that may contribute to neglect include medical illness, developmental delay, emotional or behavioral disturbance, and a lack of fit between the temperament of the child and parent. Overall factors of abuse and neglect are poverty, lack of support systems and community resources, domestic and community violence.

All instances of suspected or observed abuse and neglect must be reported. Complete information about Florida's laws on child abuse, including laws pertaining to mandatory reporting and protection of confidentiality, may be found at Department of Children and Families Child Abuse Program This program also offers educational programs for child care staff and support for families. Local Child Protection Team offices may be contacted for further information and resources.

## Infant Toddler Development Training
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**Evaluation and Assessment Considerations for Children with Neurological and/or Orthopedic Conditions**

When planning the evaluation and assessment, the team must consider the stamina of the infant or toddler. Information should be provided to the family by the service coordinator on how long the child can interact before becoming fatigued. Cardiac and respiratory endurance needs to be considered. The team must plan for postural supports such as those that can be provided by a caregiver's own body or when necessary, adaptive equipment such as an adaptive stroller, wheelchair or other seating device or stander. The infant or toddler must be in the best position to interact with the toys or test materials.

**Technological Supports**

Infants and toddlers who have neurological and/or orthopedic conditions often require assistive technology support. These may be needed during the developmental assessment or may be recommended because of the assessment. Many communities have equipment lending libraries where families may see various equipment and supports and try them on a loan basis.

**Division for Early Childhood (DEC) Technology Recommendations**

In the *DEC Recommended Practices in Early Intervention/Early Childhood Special Education* text, Kathleen Stremel (2000) outlines four technological applications for the team to consider when working with young children.

- Professionals utilize assistive technology in intervention programs for children.
- Families and professionals collaborate in planning and implementing the use of assistive technology.
- Families and professionals use technology to access information and support.
- Training and technical support programs are available to support technology applications (Stremel in Sandall et al., p. 56).

Recommended technology applications are outlined on pages 59 – 61 of the text. The ITDS should use these applications when making recommendations regarding equipment or assistive devices. It should be noted that teams need to consider low-tech options as well as high tech options.

**Community Support for Technology Services**

Families and professionals who work with infants and toddlers with neurological and orthopedic conditions can find information about technology by accessing the following websites.

- Assistive Technology
- Florida Learning and Diagnostic Resources System
- AT Links. This website provides links to the Florida Diagnostic Learning Resources Services, Assistive Technology Network. You will find curriculum ideas for all ages, a how-to sheet for making switches for toys, product lines, and multiple web links. The ideas cross all ages, therefore the ITDS will need to browse to find those most suitable for infants and toddlers. Please be patient as some of the links take a while to load. It should be noted that various levels of support are available in each local region for the team to utilize when planning appropriate technology supports for the child and family.

Another resource for children with special needs is Shriners Hospitals for Children. This is a network of 22 hospitals across North America. Since 1922, Shriners has provided no-cost medical care to children with orthopedic problems and burn injuries. The Shriners Hospital in Tampa has treated more than 30,000 patients since opening in 1985.

# Infant Toddler Development Training
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**Activity #1**

*Consider this scenario.*

The ITDS is working with Teri who has been diagnosed with osteogenesis imperfecta (OI). Teri's cognitive skills indicate that she scores above average for her problem-solving approaches, but she is very clumsy and falls a lot. Teri is constantly on the move when she is not confined to bed or in the hospital for broken bones. Ms. J., her mother, is very frightened that Teri will fall and break another bone.

1. How could the ITDS help design activities to support Teri's cognitive growth while assisting to provide the balance of protection that is needed to help prevent broken bones?
2. What strategies would you suggest to the team related to Ms. J.'s concerns?

**Activity #2**

You are the ITDS on the team for Kelly, an 18-month-old toddler, who has been diagnosed with athetoid cerebral palsy. Using your text, DEC Recommended Practices in Early Intervention/Early Childhood Special Education, list some of the applications the team could consider for Kelly.

**Lesson 4 Highlights**

This lesson provided the ITDS with an introduction to infants and toddlers who have neurological and/or orthopedic conditions. Information on how to adapt the developmental evaluation and assessment process was presented. Information to assist the ITDS to individualize the IFSP, the Plan of Care, and a Daily Activity Plan was included. Information on technological supports and community services was reviewed.

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**Websites**

- AAP Practice Guideline on Developmental Dysplasia of the Hip
- American Academy of Pediatrics
- Association for Spina Bifida and Hydrocephalus
- AT Links
- Common Orthopedic Conditions

- Department of Children and Families Child Abuse Program
- Ehlers-Danlos National Foundation
- Hydrocephalus Association
- MDA USA Breathe Easy.
- MDA USA Mitochondrial Myopathy,
- MDA USA Publication on MM
- Medline Plus Amputees
- Muscular Dystrophy Association of the USA
- National Center on Shaken Baby Syndrome
- National Organization for Rare Disorders.
- National Shaken Baby Syndrome Campaign
- NECTAC Clearinghouse
- NICHCY Specific Disabilities
- Shriners Hospitals
- Osteogenesis Imperfecta Foundation
- Seizures
- Sexual Abuse of Children
- United Cerebral Palsy Organization
- Zero to Three Publications

# Infant Toddler Development Training
# Module 6, Lesson 5

**Introduction**

This lesson presents basic knowledge related to autism and other pervasive developmental disorders and low incidence conditions in infants and toddlers. The information presented provides a foundation for planning intervention strategies with the team for young children with these conditions. This lesson provides the Infant Toddler Developmental Specialist (ITDS) with information to help the family understand and integrate developmental supports for their child.

**Learning Objectives**

Upon completion of this lesson, you will be able to:

1. Identify pervasive developmental disorders and list the five types that are included in the Diagnostic & Statistical Manual of Mental Disorders – Fourth Edition (DSM IV).
2. Recognize medical conditions, such as human immunodeficiency virus (HIV) and cancer, including causes, symptoms and their effect on the child and family.
3. Describe frequently used interventions for autism and other pervasive developmental disorders.
4. Use diagnostic reasoning to fully participate in the development of an Individualized Family Support Plan (IFSP) and Plan of Care within the context of family needs, priorities, and activities to meet the needs of a child with autism, other pervasive developmental disorders, and miscellaneous medical conditions.
5. Recognize how a child with autism, other pervasive developmental disorders, or miscellaneous medical conditions affect the dynamics within a family, including the influence on the child.
6. Access information for miscellaneous medical conditions to assist the family in planning appropriate developmental strategies to enhance their child's development and inclusion into family and community routines and activities.

**Resources**

The following resources are necessary for the completion of this lesson. Learners may wish to access and print a hard copy of the resources prior to beginning the lesson and for future reference. Some resource documents can be found in the Resource Bank. Others are available online.

- Early Intervention Positive Behavior Support
- Floor Time
- NICHCY Pervasive Developmental Disorder

**Key Words**

Definitions of key words are found in the glossary.

- Asperger's syndrome
- Congenital Heart Disease
- Echolalia
- Hemolysis
- Rett's syndrome

# Infant Toddler Development Training
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**Pervasive Developmental Disorders**

A National Dissemination Center for Children with Disabilities (NICHCY) briefing paper outlines five categories of pervasive developmental disorders (PDD) that are defined in the DSM-IV. These include:

- Autism
- Rett's syndrome
- Childhood Disintegrative Disorder
- Asperger's
- Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)

Intervention for these disorders targets strengths and deficit areas. Intervention is most effective when provided in the child's environment and focused on daily routines and activities. The ITDS works with the parent or other caregiver to assist them in identifying strategies and increasing skills that support the child's development.

**Autism and Other Pervasive Developmental Disorders**

Autism and other pervasive developmental disorders are lifelong neurological disabilities that affect a person's ability to communicate, understand language, play, and socially interact with others. The first signs of developmental delays are often noted before the age of three.

The key characteristics, sometimes referred to as core deficits of autism, are those the child demonstrates. They include:

- a disturbance in social interactions,
- a disturbance in communication (language skills), and
- rigid or repetitive or stereotypic behavior or thinking.

These characteristics must be present before the age of five years even if the condition is not diagnosed until a later age. Parents are usually the first to notice unusual behaviors in their child. In some cases, the parents report that their baby seemed "different" from birth. When compared to a typically developing child, a young child with autism is often less responsive to people and does not engage in many of the typical nonverbal social behaviors. Autism is classified as a developmental disability because it interferes with the typical rates and patterns of childhood development. There are diagnoses closely related to autism such as pervasive development disorder not otherwise specified (PDDNOS), Asperger's syndrome, and Rett's syndrome that are included in the category of Pervasive Developmental Disorders (PDD).

The following sections will provide a discussion of the three core deficits often recognized for the child with autism or other pervasive developmental disorders. Sometimes pervasive developmental disorders are referred to as autism spectrum disorders, but they will be referred to as pervasive developmental disorders (PDD) in this lesson.

1. *Social Interactions*

This core deficit in reciprocal social interactions is one of the hallmark features of autism or other pervasive developmental disorders. Some of these social differences include a lack of showing, pointing, or following objects, a lack of spontaneous seeking to share enjoyment with their caregiver, being non-responsive to their name, and poor to non-existent eye-contact. Children with pervasive developmental disorders such as autism may resist attention or passively accept hugs and cuddling. They may not seek comfort from others. The young child with autism often prefers to be left alone or to gaze at favorite objects for extended periods of time. To parents, it may seem as if their child is not bonding with them. Parents may feel crushed by this.

Children with a pervasive developmental disorder such as autism do not understand social cues, such as tone of voice or facial expressions and have difficulty interpreting what others are thinking or feeling. They may initially appear to develop typically and then begin to withdraw or become indifferent to social interactions at age two or three.

2. *Communication*

Verbal and nonverbal communication is another core area of concern for children with a pervasive developmental disorder such as autism. Specifically, children with autism usually demonstrate a delay in, or total lack of, spoken language, and may refer to themselves by their name instead of "I" or "me." If they possess language, they usually demonstrate an inability to initiate or sustain even a simple conversation. They may engage in stereotypical or repetitive use of language such as immediate or delayed echolalia or use words in an idiosyncratic manner.

Some children demonstrate unusual prosody such as speaking in a stiff, nasal, jerky or sing-song tone of voice. Their range of favorite topics is often very restricted, with little regard for the interests of the other person. While it can be hard to understand what children with autism are saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what the child with autism is saying. Without meaningful gestures or language, children with autism are at a loss to let others know what they need. As a result, they may simply scream or grab what they want.

3. *Behavior*
   Restricted and repetitive behaviors or interests are the third, and final, core deficit area for children with autism. Many children with autism engage in repetitive movements or posturing such as rocking or twirling, hand or finger-flapping and toe-walking. Some may also engage in self-abusive behaviors such as biting or head-banging.

   Young children with autism may demonstrate an inability to play with a variety of toys or will use the toys in non-functional or unconventional ways, such as lining up objects or spinning the wheels on a car rather than rolling it along the floor. Children with autism also have difficulty with the concept of fantasy or make-believe play and they are unable to play interactively with other children. Finally, children with autism often demonstrate an inflexible adherence to specific, nonfunctional routines and rituals and will become extremely upset if these routines or rituals are not strictly followed.

**Sensory Concerns**
In addition to the core deficit areas described above, many children with autism have a reduced sensitivity to pain, but are hypersensitive to sensations such as sound, touch, or other sensory stimulation. These different sensitivities may contribute to behavioral symptoms such as a resistance to cuddling or hugging. A child with autism may fall and break an arm, yet never cry. Another may bash his head against a wall and not wince, but a light touch may make the child scream with alarm.

Each of the symptoms within the three core deficit areas, as well as the sensory issues, range on a continuum from mild to severe and will present differently in each child. However, all children with autism will display communication, social, and behavioral deficits to some degree.

## Infant Toddler Development Training
## Module 6, Lesson 5

**Specific Intervention Strategies for Autism**

There is no single "best treatment" for every child with autism. One point, on which most professionals agree, is the importance of early intervention. Another is that most individuals with autism respond well to highly structured, specialized programs.

The following are examples of a few intervention strategies proven to be effective for children with autism.

**Positive Behavior Support**

Positive Behavior Support (PBS) is a process for understanding and resolving the problem behavior of children that is based on values and empirical research. It offers an approach for developing an understanding of why the child engages in problem behavior and strategies for preventing the occurrence of problem behavior while teaching the child new skills. Positive behavior support offers a holistic approach that considers all factors that impact on a child and the child's behavior. It can be used to address problem behaviors that range from aggression, tantrums, and property destruction to social withdrawal. PBS contains the following components:

- Behavior Hypothesis Statements - Statements that include a description of the behavior; triggers or antecedents for the behavior, maintaining consequences, and purpose of the problem behavior.
- Prevention Strategies - Strategies that may be used to reduce the likelihood the child will have problem behavior. These may include environmental arrangements, personal support, and changes in activity; new ways to prompt a child, changes in expectations, etc.
- Replacement Skills - Skills that will replace the problem behavior.
- Consequence Strategies - Guidelines for how adults will respond to problem behaviors in ways that will not maintain the behavior. In addition, this part of the plan may include positive reinforcement strategies for promoting the child's use of new skills or appropriate behavior
- Long Term Strategies - Includes strategies that will assist the child and family in meeting their long-term goals.

**Applied Behavior Analysis**

Applied behavior analysis (ABA) has become widely accepted as an effective treatment strategy for children with autism. Many years of research demonstrate the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones. An effective treatment program will build on the child's strengths and interests. It will offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior.

Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to offer training to parents so they may continue the therapy at home.

Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a

childcare center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction.

**Visual Supports and Environmental Strategies**

Visual tools and supports help create an environment that is predictable and understandable to the child with autism. This will make communication, social, and behavioral difficulties less likely to occur. The purpose of using these aids is to enhance the child's understanding of what is happening and what is expected. Although the primary purpose of these tools is to support communication, they are also used to give information, provide structure, etc.

Children with autism tend to be visual learners living in a very auditory world. Visual supports focus on the strength of the child. Thus, children with autism often learn more if the ITDS and caregivers use visual rather than auditory teaching strategies. These techniques work for verbal, as well as non-verbal, children. Implementing a system of visual tools and supports significantly reduces various behavior problems and increases effective communication and interactions. Some examples of visual supports and environmental strategies include daily activity schedules, task analysis visual aids, checklists, mini-schedules, choice boards, and 'First-Then' choice boards.

**Integrated Play Groups**

Integrated play groups, first developed by Pamela Wolfberg (1987, 2004), are an effective means for teaching appropriate social interactions and play skills with peers. During the process of functional play groups, the adult mirrors the child's play and directly teaches play imitations with the toys. The situations are highly structured to assure attending and practice, using carefully planned themes and materials. Other strategies within the realm of functional play might include Pivotal Response Training (PRT) and Incidental Teaching.

**Social Skill Strategies**

Strategies for teaching and enhancing social skills have been found to be effective for some children. One of the best strategies to teach social skills is using Social Stories, which were developed by Carol Gray (1996, 2004). These scenarios describe social situations along with their relevant social cues. Social Stories provide information on what is occurring and why. They explain the perspective and experiences or behavior of others. Power Cards, developed by Elisa Gagnon (2001), are another social skill strategy. These consist of small, visual aids that use the child's special or unique interest to motivate and teach appropriate social interactions. A final strategy is the use of visual scripts. These clarify choices in social situations, provide an actual 'script' of upcoming events or conversations and reduce the child's anxiety by assisting with conversation starters.

**Conclusion**

Autism can be complex, severe, and frightening. But it is not hopeless. With the help of good intervention and services, many individuals with autism can make excellent progress and achieve integration within their community.

# Infant Toddler Development Training
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**Role of the ITDS**
Neither the ITDS, nor the Early Steps team, make a diagnosis of autism or the differential diagnoses of the PDD Spectrum.

Given the statement above, name at least two ways the ITDS can contribute to the team.

Consider what you would look for as early signs of behavioral disturbance in young children with a suspected diagnosis of autism. What should the ITDS be looking for (monitoring) when working with children with this diagnosis?

**Autism Resources**
The two resources listed below are required reading and are in the Resource Bank. This material will be valuable for completing activities #4 and 5 later in this lesson.

- Early Intervention Positive Behavior Support
- Floor Time

For a comprehensive listing of other resource materials for infants and toddlers recommended by experts in the field of early childhood care and education, the ITDS may want to check out material that can be ordered through Zero to Three Publications. Resources the ITDS can access for planning intervention strategies can be found on several websites. Information on autism and related disorders, applied behavior analysis and positive behavior support, including suggestions for intervention, can be found at the following:

- Center for Autism at USF
- Center for Autism at UF

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**Miscellaneous Medical Conditions**
**Sickle Cell Disease**
Sickle Cell Disease is the most common genetic cause of a structural abnormality of hemoglobin, producing anemia in people of African and Caribbean descent. The disease causes an amino acid substitution during synthesis of food thus resulting in abnormal hemoglobin in the blood stream.

Although newborns with sickle cell disease appear to be normal at birth, by 4 to 6 months of age, the infants become anemic and some of their red blood cells appear to have a sickle shape rather than the nicely rounded edges of normal red blood cells. The sickled cells can cause Vaso occlusion (blockages in the blood vessels). The infants show signs of swelling in their digits (fingers and toes) that is quite painful and enlarged organs (organomegaly). These young children are at risk for overwhelming infections but, when detected, can be protected against certain bacterial organisms with antibiotic prophylaxis, and vaccination.

The Vaso occlusion can cause local tissue hypoxia (lack of oxygen), and at times ischemia (disruption of blood flow in any area of the body that can lead to tissue death) and infarction (rupture of a blood vessel that prevents blood flow and can lead to tissue death).

Infarction produces pain in the form of Vaso occlusive crises, especially in the extremities. A person who has sickle cell disease is prone to leg ulcers later in life. The kidneys can have infarction resulting in blood in the urine. An infarction in the brain may result in a stroke. This is a devastating complication for children. Retinopathy with resulting visual loss can occur, though this is rare in young children.

An occlusion may occur in the gastro-intestinal tract and cause severe pain. An excessive breakdown of the red blood cells leads to "bilirubin" gallstones. This condition contributes to hepatomegaly (enlarged liver) and enlarged spleen. The liver is also enlarged because more red cells are produced.

The spleen becomes enlarged early in the disease, but as time goes on, the spleen quits functioning due to infarctions and shrinks. With a nonfunctioning spleen, the child becomes very susceptible to bacterial infections that are very resistant to antibiotics. Very rarely, the spleen will fill itself with a large quantity of circulating blood in a condition known as a "sequestration" crisis. This results in shock and the child requires immediate resuscitation.

Usually, the sickle cell disease is detected with newborn screening for abnormal hemoglobin. Early identification assists in the early planning for medical management and genetic counseling.

**Clotting Disorders**
Severe problems with bleeding do not occur with every child with a clotting disorder. However, in the most widely known clotting disorder, hemophilia A (Factor VIII deficiency), bleeding can occur several times a month, and require visits to the hospital or acute care clinic for clotting factor therapy.

A major issue for a child who has a clotting disorder is trauma. Trauma can produce major bleeding into the joints (hemarthroses). When the blood is reabsorbed, the joint lining is broken down and this leads to joint degeneration. Movement becomes painful and limited. Rehabilitation is uncomfortable, but necessary to prevent further debilitation.

Bleeds into the brain can destroy both gray and white matter. There is an increased risk of seizures leading to an increased incidence of learning difficulties.

The use of blood derived products for the treatment of hemophilia brings with it the risk of infections such as hepatitis B, hepatitis C, and Human Immunodeficiency Virus (HIV). This is a major concern for both parents and other caregivers.

Parents and caregivers must be constantly vigilant to safeguard the young child from injury. It is hard for parents to allow their children with hemophilia to be independent. Parents and caregivers must be aware that the use of corporal punishment or even grabbing a child's hand can result in a bleed.

Consider how the ITDS can help the family of a child with a clotting disorder. Name at least two ways.

To understand immune deficiency, the ITDS must first understand immunity. Immunity involves cellular and chemical elements. The mark of a healthy immune system is the ability of the body to respond to foreign material through the process of inflammation.

The signs of inflammation are redness (rubor), heat (calor), pain or tenderness (dolor), swelling (tumor), and functio laesa (loss of function). These inflammatory symptoms are present in the blood vessels or adjacent tissues when a foreign agent is introduced into the body or when an injury to the body has occurred. The process of inflammation is part of a healthy body's natural protection and repair mechanism. In this process, cellular elements, such as white blood cells in the blood stream and tissues, and chemical elements, such as immunoglobulins, work to repair and protect the affected area. Immunoglobulins produce antibodies that are part of the body's natural defense against infection.

Pathophysiology is when the body's natural immune processes are not working properly. The processes may be out of balance and the immune system overreacts (autoimmune) and fights its own cells or certain elements are missing or lacking (immune deficiency) and the body cannot fight infection. Immune deficiencies include allergies, cancers, and isolated blood disorders. Many of the conditions are genetic in origin.

Unlike the genetic immune deficiencies, human immunodeficiency virus or HIV infection is an acquired immunodeficiency. Millions of people have been infected with HIV worldwide. There are approximately 1.4 million children infected and about 34 million adults. Perinatal transmission (vertical transmission from mother to baby during the birth process) accounts for 90% of HIV infections in children. The risk of perinatal transmission drops from 25% to 1- 2 % with proper medical care in both the prenatal and postnatal period. Screening of pregnant women is essential.

There are measures that significantly reduce the risk of the baby becoming infected from a mother who has HIV. Pretreatment of both the mother and the baby with a drug known as AZT before and after delivery greatly reduce the risk of infection in the infant. Proper nutrition is of paramount importance to assist in fighting off infection. HIV in children is identified by 1 month of age or excluded by 6 months of age with final confirmation of exclusion by 18 months of age.

Consider interventions that the medical and developmental team are aware of when treating a child with HIV. Remember that the ITDS will be working with doctors, nurses, and social workers.

Consider the most important intervention that all team members must remember when providing care for a child with HIV to reduce the risk of infection.

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**Cancer**

Cancer is the result of a failure of the body to regulate cell production. The result is a proliferation of abnormal cells in abnormal numbers and places. In the United States, there are 8,000 - 9,000 children diagnosed with cancer each year.

Common sites for cancers in children include muscle and bone (sarcomas), blood (leukemias), lymph nodes (lymphomas), the brain and nervous system (neuroblastomas), the kidneys (renal tumors), the eyes, and other soft tissues. A cancer may be diagnosed by the presence of a mass lesion or by the symptoms that are associated with the lesion. For example, a bone lesion may cause bone pain and limping as the first symptoms. Cancers of the blood may manifest through unexplained bleeding, bruising, or pallor. Cancers of the brain and/or central nervous system may cause headaches and vomiting. Kidney (renal) cancers may result in blood in the urine, pallor, and urinary tract obstruction.

There may be swelling of the affected part of the body such as the face or neck when the cancer is present in soft tissue. There may also be obstructions in the airway. Cancers of the eye may first be detected seeing what appears to be a white spot on the pupil. Non-specific symptoms can include weight loss, diarrhea, low-grade fevers, malaise, and failure to thrive.

**Cancer Treatments**

Treatment of the child's cancer is overseen by a pediatric oncologist, a doctor who is a specialist in cancers, together with the child's primary medical doctor. Treatments can include surgery, chemotherapy, radiation therapy, bone marrow or blood stem cell transplants, and immunotherapy. Treatment is determined by three factors:

- type of cancer,
- extent of the disease at the time of diagnosis, and
- balance of the efficacy of the treatment with the toxicity associated with the treatment.

Purposes of surgery include obtaining a specimen to determine the extent of the disease and to specify the type of cancer, removing the tumor mass to relieve symptoms, and inserting intravenous lines. The purpose of chemotherapy is to interrupt the cell cycle of proliferation of the abnormal cells while also minimizing the damage to normal cells. Most of the commonly used chemotherapeutic agents interrupt the cell cycle and cause breakage to the DNA strands to interrupt cell division. Often chemotherapy and radiation therapy are used in combination.

Transplantation is used to assist the body to grow more normal cells while reducing the number of abnormal cells. Immunotherapy is the administration of medicines that use the immune system to fight the cancer.

What family issues should the ITDS remember when working with a family of a child who is undergoing treatment for cancer?

What important information should the ITDS remember about the prognosis for children who have various forms of cancers?

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**Congenital Heart Disease**

The normal heart has four chambers that pump oxygenated blood from the lungs to all parts of the body and return blood that contains carbon dioxide from the tissues back to the lungs for excretion. This process is necessary for cell maintenance and repair.

Infants may be born with a defect of the heart. Some common defects include a Ventricular Septal Defect (VSD), Patent Ductus Arteriosus (PDA), Tetralogy of Fallot, coarctation of the aorta, Atrial Septal Defect (ASD), pulmonary stenosis, transposition of the great arteries, and hypoplastic left heart syndrome. Less common is a defect where an infant is born with only two or three chambers in the heart rather than four.

The following few sections will provide a detailed discussion of defects of the heart. The ITDS needs basic information about these conditions.

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  - **Endocardial Cushion Defect** (Atrioventricular or A-V Canal Defect) is a large hole in the center of the heart where the wall between the upper chambers joins the lower chambers. The defect also involves the heart valves. Instead of two separate valves, there is a single valve. The defect causes a mixing of oxygenated blood with un-oxygenated blood. Blood is pumped back into the body without an adequate supply of oxygen. The condition may result in high blood pressure and heart value regurgitation (blood leaking backward from the lower to the upper chambers).
    Infants with this condition, which is common in Down syndrome, usually have an enlarged heart. They breathe rapidly and have upper respiratory infections. They tend to have poor appetites and are undernourished. Surgery is required to correct the defect. Even after surgery, the child needs to be followed by a cardiologist. A child with an endocardial cushion defect needs prophylactic antibiotics prior to dental work to prevent infection.

  - **Ventricular Septal Defect (VSD)** is the most common heart lesion. This is a hole in the wall between the ventricles, the two bottom pumping chambers. Some occur in isolation, and some occur in combination with other conditions. VSDs usually do not present symptoms at birth. If the defect is large, it can result in congestive heart failure by 6 - 8 weeks of age because the blood is shunted from the left to the right ventricle producing an overload on the right side of the heart. The condition can result in a failure of the heart to pump enough blood into the tissues. Fluid becomes backed up in the heart and into the lungs causing difficulty breathing.

Many small VSDs spontaneously close and only present with a murmur. Moderate to large defects may need surgical correction. However, non-invasive procedures for repair are more often used today including "stents" and "umbrella patches". If treated promptly, there is minimal to no long-term sequalae. Infants are the most ill when they are very young and must be under the care of a pediatric cardiologist who will assist the family with nutrition and monitor appropriate activity levels.

What medical professions will be available to the ITDS for consultation when the ITDS is working with a child who has VSD?

When should developmental stimulation activities be initiated by the ITDS for a child who has a VSD?

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    - **Patent Ductus** is the persistent patency of the blood vessel connecting the aorta and the pulmonary artery that normally closes at birth. However, for some infants it remains open and can cause congestive heart failure. A medicine, indomethacin, may be used to facilitate the closing of the patent ductus. If the defect does not respond to this medicine, then surgery may be required and usually effectively corrects the problem.
    - **Tetralogy of Fallot** is a combination of four lesions: a VSD, pulmonary stenosis, an overriding aortic valve, and right ventricular hypertrophy. The condition causes cyanosis (blueness due to lack of oxygen in the tissues). The infant might need a shunt to improve oxygenation. Other surgery to repair the defect is delayed until the infant is a little older.

What considerations for intervention would the ITDS need to consider for a child who has a Tetralogy of Fallot?

- **Coarctation of the Aorta** or narrowing of the aorta, when present in combination with other heart problems or when severe can present in the newborn period with cyanosis and heart failure. However, it usually presents later with a murmur and discrepant blood pressures when the blood pressure is taken in both arms and legs of the child. The condition causes hypertension. Surgical repair is determined based on the location of the lesion and whether other anomalous structures are present.
- **Atrial Septal Defects (ASD)** often go undiagnosed because everyone is born with a small opening between the two upper chambers of the heart, a patent foramen ovale that closes right after birth when the patent ductus closes. However, some reopen or stay open. In addition, there can be defects in other places in the atrial septum (between the two top chambers of the heart). These defects can usually be closed with a procedure called an "umbrella" patch.
- **Pulmonary Stenosis** is a narrowing of the pulmonary valve. This valve allows blood to flow from the right ventricle of the heart to the pulmonary artery so that the body's blood can be re-oxygenated. When the opening is too narrow, the body does not receive enough oxygenated blood to maintain cellular function. Pulmonary stenosis is a congenital defect and can often be corrected with surgery. Severe pulmonary stenosis causes a child to be very ill.

- **Transposition of the Great Arteries** is when the aorta and the pulmonary artery come out of the wrong ventricles of the heart. The blood that is returned to the body is not re-oxygenated and the baby appears very blue. The oxygenated blood that should go to the body is returned to the lungs. The baby is given a medicine called “prostaglandin” to keep the ductus open so that the body receives at least a small mixture of oxygenated blood with the blood that is pumped from the heart. Surgery is required to correct the defect.
- **Hypoplastic Left Heart Syndrome** is very rare but is very serious. The whole left side of the heart is underdeveloped. This includes the aorta, the aortic valve, the left ventricle, and the mitral valve. An infant who has this rare condition often dies in the first week of life. The treatment for the condition is a heart transplant.

Some heart defects are treated with patching, a micro-surgical procedure that has reduced the risk to a child for open-heart surgery. However, open-heart surgery is still required in some circumstances. For a very small number of children, the only option for treatment is a heart transplant. The outcome of a heart transplant can be quite good if the threat of immunologic rejection is managed. To learn more about these and other heart conditions of infants and toddlers, the ITDS can access information from the Texas Heart Institute

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**Individualizing the IFSP to Address Health Issues**

When a child has health issues that affect development, a team approach is essential. The primary medical doctor and all specialists should be consulted (with the family's signed permission) so that developmental strategies are not in conflict with medical protocols. In planning for a child with a cardiac condition, the team must assess the type and amount of activity that the child can tolerate with the child's need for oxygen and rest. The ITDS needs to be mindful that an infant or toddler will need more rest during the session. Skin color and respiratory rate and depth must be noted as activities are incorporated into the daily routines. Sometimes the team will decide that the best intervention is to delay an initiation of developmental activities until the heart repair is made.

**Resources for Miscellaneous Medical Conditions**

Children's Medical Services is Florida's agency that serves children with special health care needs. It is located within the Florida Department of Health. There is a local Children's Medical Services (CMS) program in every region of the state. The CMS program has information on chronic health conditions that affect infants and toddlers. The ITDS should be familiar with this resource so that information can be shared with families.

## Infant Toddler Development Training
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**Activity #1**

*Consider this scenario.*

Gerri, a 28-month-old child who has just been diagnosed with autism has been referred to you as the ITDS. During your first session, Gerri's mother asks you for your opinion about different approaches to intervention such as Applied Behavioral Analysis.

How would you respond?

**Activity #2**
Review the NICHCY Pervasive Developmental Disorder fact sheet and answer the following questions.

1. How is PDD characterized in the DSM-IV according to this fact sheet?
2. What are the criteria for the diagnosis of PDD?

**Activity #3**
*Consider this scenario.*
As the ITDS you have been asked to provide developmental interventions to a 4-month-old infant who has Tetralogy of Fallot.

What considerations will you make when planning activities for this child?

**Activity #4**
Earlier in this lesson, you looked at the Floor Time material from Dr. Stanley Greenspan. Many concrete strategies were included in this reading. Go back to this material again. Select five strategies that would be useful to you in helping a child develop motor planning abilities.

**Activity #5**
You read about the value of Early Intervention Positive Behavior Support earlier in this lesson. In the material, you learned that problem behavior is viewed as having meaning or serving a purpose for the child. This purpose is identified through a process. Can you remember what this process is called?

**Lesson 5 Highlights**
This lesson provided the ITDS with an introduction to infants and toddlers who have pervasive developmental disorders, and miscellaneous medical conditions that affect development. Information to assist the ITDS to individualize the IFSP, using a team approach was included. Information on community supports and services was reviewed.

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**Websites**

- Autism Society of America
- Autism Society of Florida
- Center for Autism at USF
- Center for Autism at U of F.
- Center for Evidenced Practice: Young Children with Challenging Behavior
- Center on the Social and Emotional Foundations for Early Learning
- Families for Early Autism Treatment
- Floor Time
- Florida State University CARD Center
- Integrated Play Groups
- Kids Health and HIV/Aids Nemours Foundation
- Kids Health Index of Infections Nemours Foundation
- Kids Health and Sickle Cell Anemia Nemours Foundation
- National Alliance for Autism Research
- National Institute of Child Health and Human Development
- National Institute of Mental Health
- National Institute of Neurological Disorders
- Social Stories
- Solving behavior problems in autism using visual strategies
- Texas Heart Institute
- University of Central Florida CARD Center
- University of Florida at Gainesville CARD Center
- University of Miami CARD Center
- University of South Florida CARD Center
- Zero to Three

# Infant Toddler Development Training
# Module 6

**Congratulations!**

You have completed Module 6. You may want to review the Module before taking the Module 6 Final Assessment on TRAIN. **Please contact your local Early Steps TRAIN to enroll you in these modules through the TRAIN learning management system**

## Module 6 Resources

- Florida's Individualized Family Support Plan (IFSP)
- Food Insecurities
- Looking at Metabolism
- Plan of Care
- Weight-for-age percentiles: Boys, birth to 36 months
- Weight-for-age percentiles: Girls, birth to 36 months
- Length-for-age percentiles: Boys, birth to 36 months
- Length-for-age percentiles: Girls, birth to 36 months
- Weight-for-length percentiles: Boys, birth to 36 months
- Weight-for-length percentiles: Girls, birth to 36 months
- Head circumference-for-age percentiles: Boys, birth to 36 months
- Head circumference-for-age percentiles: Girls, birth to 36 months
- Albinism
- All About Strabismus
- Amblyopia
- Cortical Visual Impairment
- Eye Specialists
- Eye Specialist Report
- FDOE Cochlear Implants Memorandum
- FDOE Cochlear Implants Technical Assistance Paper
- How the Eye and Brain Work Together
- Optic Nerve Hypoplasia
- Optic Nerve Atrophy
- Parent Interview Protocol for Child Hearing and Vision Skills
- Part C: Criteria Specifying Visual Impairment
- Pediatric Visual Diagnosis Fact Sheet Set
- Retinal Diseases
- Retinopathy of Prematurity
- SHINE Case Examples
- SHINE Communication Building Blocks
- SHINE Early Listening Function Questionnaire
- SHINE Functional Outcomes
- SHINE Index
- SHINE Plan of Care
- SHINE Procedural Safeguards
- Visual Assessment
- NICHCY Epilepsy
- NICHCY Cerebral Palsy
- NICHCY Spina Bifida
- Early Intervention Positive Behavior Support
- Floor Time
- NICHCY Pervasive Developmental Disorder