III. HEALTH AND NEURODEVELOPMENTAL SUPERVISION FOR THE LOW BIRTH WEIGHT NEONATAL INTENSIVE CARE UNIT GRADUATE

HEALTH OUTCOMES

As a group, low birth weight children experience more health problems than normal birth weight children, and require special attention to some aspects of routine well-child care.

Immunizations:

The appropriate age for initiating most immunizations for the premature infant is inaccordance with the chronologic or uncorrected age. There should be no alteration of vaccine dosage. The following exceptions apply:

1. **Influenza vaccine**
   a. Family contacts and other caregivers of infants born prematurely and infants with other chronic conditions should receive influenza vaccine.
   b. For preterm infants in whom chronic respiratory tract disease develops influenza vaccine should be administered annually in the fall once they have reached 6 months of age.
2. **Hepatitis B**
   Optimal timing of immunization for the preterm infant with a birth weight less than 2kg whose mother is Hepatitis B surface antigen negative has not been determined. Current AAP Redbook recommendations (2000) are to: 1) delay Hepatitis B immunization for this subpopulation until just before discharge from neonatal hospitalization if the infant then weighs 2 kg or more, or 2) until approximately two months chronologic age when other immunizations are given.
3. **Respiratory Syncytial Virus** – Infants born at 32 weeks gestation or less, even without CLD, may benefit from RSV immunoprophylaxis. See the AAP Policy Statement for RSV Prevention (Pediatrics 112(6): 1142-1146, 2003) or the latest edition of the AAP Red Book for the most current recommendations.

Growth: Many low birth weight infants with growth appropriate for gestational age (AGA) deviate from expected growth curves during their neonatal hospitalization and during periods of chronic or acute illness. Some of these AGA infants remain under the 10th percentile in height and weight parameters beyond three years of age with gradual catch up to their genetic potential by 6-8 years of age or later.

In contrast, infants less than 10% birth weight, small for gestational age (SGA), often remain small. Prognostically, there is a greater chance of catch-up growth in an SGA infant with normal intrauterine head growth. Catch-up head growth usually precedes catch-up in length and weight and is generally seen between 36 weeks postconceptual age and 8 months. Very little catch-up growth occurs in head size after one year of age. Infants with chronic medical conditions may not experience catch-up growth until school age.

Breast Feeding: Full-term, premature, and SGA infants all benefit from breast feeding. Studies indicate that premature infants and SGA infants who are breast fed have a significant intellectual advantage (higher IQ scores) over non-breast fed peers.[5, 6]

Feeding Issues: Feeding difficulties may surface in the first days and weeks post hospital discharge. Many LBW infants have difficulty sending clear behavioral cues to their caregiver, lack endurance, and become easily overstimulated resulting in stress during the feeding for both the family and the infant. Nursing support or the assistance of a feeding specialist with expertise in infant feeding (often either an occupational therapist or speech therapist) may be indicated. These specialists can help optimize reading infant's cues, and review positioning and feeding techniques. Lactation consultants, particularly those familiar with LBW infants, may be helpful to breast-feeding mothers and infants. Additionally, parental comfort with infant feeding and

knowledge of formula preparation must be monitored. Registered dietitians may be consulted for growth and nutritional assessment.

Among LBW infants experiencing a relatively benign NICU course, those most at risk of nutritional problems after discharge are infants with:

- Very low birth weight (≤1500 g birth weight)
- Extremely low birth weight (≤1000 g birth weight)
- SGA
- Feeding problems while in the NICU, which may include requiring extra time with lactation consultant
- Special formulas needed to sustain growth
- Parenteral nutrition > 4 weeks
- Bronchopulmonary dysplasia or other respiratory compromise
- Anemia
- Neurological damage
- Short gut syndrome
- GE reflux

Infants with any concerns in the above areas warrant close monitoring of nutrition with weekly or twice-weekly weight checks until a satisfactory growth rate is established. If the growth is not adequate, assessment of cause should be made with consideration of referral to a pediatric registered dietitian.

Failure to grow (FTG) is the failure to grow at the expected rate, with a downward shift across growth channels on standardized growth charts. FTG is more frequent in the low birth weight infant, especially infants with cardiorespiratory problems, gastroesophageal reflux disease, and neurodevelopmental problems

The risk of FTG is increased in LBW cildren who start solids earlier than 4-6 months corrected age and with the early use of cow's milk (prior to 12 months corrected age) or lowfat milk prior to 2 years of age.

Additional factors to consider in a child who is failing to grow include: anemia, physiologic/metabolic disorders, oral and motor dysfunction, neurobehavioral differences, family stress, family dysfunction, potential child abuse or neglect, other chronic health problems.

Some LBW infants need special attention to choice of formula (e.g. need to continue on enhanced preterm formulas) and caloric density of formula for optimal growth to occur. It is also important to be alert to medical complications affecting feeding such as gastroesophageal reflux disease (GERD), short gut, cardiorespiratory or neurodevelopmental complications including swallowing dysfunction and incoordination, and anatomic factors such as deep palatal grooves post-intubation. At times further evaluation such as feeding assessment, oral motor assessment, and/or radiographic swallowing study will be needed.

Transitions to semi-solids and from breast/bottle to cup should be based on corrected age and developmental readiness, **not** on chronological age. Developmental readiness for solid foods is signaled by the infant's interest in and reaching toward other family member's food, and good head control in the upright sitting position.

Behavioral Organization/Self-Regulation: Clinical research by Brazelton, Als and others has impacted the understanding of the neonate's emerging physiological and behavioral adaptation to his environment. Als' individualized developmental care model describes the infant in behavior along three channels of communication: the autonomic system (breathing patterns, color fluctuation, tremors, startles), the motor system, (body tone, postural repertoire, and movement patterns), and the state organizational system (range, robustness, modulation, and patterns of transition states).[7] This model states that infants can communicate their stress limits and levels of stability through their behavior and that infants are in continual interaction with their environment through these functional subsystems. Approach and avoidance self-regulatory behaviors can be documented for an infant. An observation of the infant through these systems can clarify the emerging behavioral organization of the infant and assist families in understanding their infant's signals. At discharge from the NICU and in the continuing months ahead it is beneficial to the LBW infant that his caregivers continue to take into account the still emerging organization and integration of these systems.

Caregivers can support the infant by:

- protecting the infant from environmental stimulation as needed
- reading the infant's behavioral messages
- promoting the infant's self-regulatory behaviors
- providing supportive positioning and handling
- gently encouraging the infant's orientation to visual and auditory stimuli as alerting emerges, and planning daily caregiving routines around the times the infant is best able to cope with handling

Gastroesophageal Reflux Disease: GERD is more commonly seen in LBW infants than full term infants. Reflux may contribute to failure to grow adequately, chronic cough, choking, and aspiration causing setbacks in respiratory healing. GERD can cause recurrent aspiration, apnea and/or bradycardia, " feeding aversion", anemia, otalgia, and dental erosions. Children often alter feeding patterns because of the inflammation and presumed discomfort associated with reflux esophagitis. Although GERD may be diagnosed prior to NICU discharge, it is important to realize that the first symptoms of GERD may not present until the initial weeks and months at home. In a LBW infant with persistent feeding difficulties, consider occult GERD. Attention to positioning after feedings, and adjusting the volume and frequency of feedings are helpful management strategies. Medical, and potentially surgical, treatment is available and should be considered with significant GERD. Diligent, ongoing medical management using motility agents and /or medications to reduce gastric acid may be necessary with subspecialist referral as needed.

Anemia: During the first year of life, low birth weight infants are at high risk for anemia, which leads to an increased risk of neurodevelopmental sequelae and failure to grow. Maternal iron stores are transferred to the infant during the last trimester of pregnancy. The more premature the infant, the fewer the iron stores available for erythropoiesis. In addition, iatrogenic blood losses from the neonatal hospitalizations are often quite significant and, if the infant required transfusion in the NICU, there is subsequent suppression of red blood cell synthesis. Iron supplementation for the LBW infant (2-4 mg/kg/day) should start by 2 months postnatal age rather than at 6 months, as recommended for the full term infant. Iron fortified cereals and formulas are not enough. Ongoing monitoring of hematocrit and/or hemoglobin is needed.

Parents are sometimes concerned about "constipation due to iron" and want to reduce their infant's iron intake. Constipation is usually of multifactorial etiology, with the most common cause being insufficient fluid intake. For problematic constipation, a careful assessment, potentially including a nutritional consultation, should be performed.

Respiratory: Complications of intubation such as subglottic stenosis, tracheomalacia, vocal cord paralysis, laryngeal granulomas, longitudinal palatal grooves may adversely affect dentition, speech and hearing, and the incidence of middle ear disease. LBW infants may have chronic lung disease and may be discharged home on oxygen with the need to be monitored for adequacy of oxygenation and ability to be weaned from this supplemental oxygen. In addition, continuing attention should be given to preterm infant car seat fit and positioning.[8]

The most common respiratory conditions found in this population are chronic lung disease, upper and lower respiratory tract infections, and otitis media. Children may present with rales, cough, retractions, stridor at rest, and/or prolonged expiratory phase of breathing. Children may later experience difficulty with decreased exercise tolerance. Respiratory compromise can continue in to young adulthood. Abnormal pulmonary function tests may be related to complications of neonatal respiratory compromise or familial factors.

Increased risk of infection due to environmental exposures (e.g., daycare) and household exposure to direct airway irritants (e.g., smoke from cigarettes, fireplace, or woodburning stove) are important considerations for this population. Infants born at 32 weeks gestation or less may benefit from RSV prophylaxis (see the AAP Policy Statement, the latest edition of the AAP Redbook or consult a pediatric pulmonologist for the most recent recommendations).

Sudden Infant Death Syndrome (SIDS): Prematurity and low birth weight are two of the

consistently identified risk factors for SIDS. The National Institute of Child Health and Human Development SIDS Cooperative Epidemiological Study found infants born at less than 2500 grams to be five times more likely to die of SIDS and infants with birth weights less than 1500 grams eighteen times more likely to die of SIDS than controls.[9] Maternal smoking during pregnancy increases the SIDS risk 3 to 4 times. For full-term infants the peak incidence of SIDS is between three and four months postnatal age. In the preterm population, the peak incidence of SIDS is at more than 43 weeks postconceptual age for preterm infants of any gestational age.[10]

SIDS is the most common cause of post-discharge infant mortality, although the incidence has been decreasing with increased attention to supine sleeping posture in infants. Recommendations for sleep position for some children with chronic lung disease, upper airway malformations, and GERD must be individualized and may require apnea or sleep studies to assist in decision making. Some preterm infants with apnea persisting to discharge are sent home on methylxanthines and an apnea monitor. While home monitoring may be used to document apnea, bradycardia, or hypoxia, there is no evidence these are associated with an increased incidence of SIDS. Further there is lack of evidence that home monitoring has any impact on SIDS prevention, including in the preterm population.[11]

Cardiac Complications: In the rare child discharged home with a Patent Ductus Arteriosus (PDA), spontaneous closure may still occur up to 4-6 months post discharge. Continued monitoring for congestive heart failure and need for medical or surgical intervention is needed.

The use of umbilical artery catheters in the NICU patient is associated with an increased risk of thrombus formation, vasospasm, and occasionally, secondary hypertension in infants. Infant blood pressure is difficult to measure accurately because infants and toddlers are usually upset by the discomfort of the cuff and pressure of inflation. Accurate blood pressures may be easier to measure when the infant is in deep sleep in the parent's lap.

Right ventricular hypertrophy can be a complication of severe bronchopulmonary dysplasia and pulmonary vascular hypertension associated with hypoxemia. Systemic hypertension is seen in infants and young children with chronic lung disease and generally responds well to antihypertensive agents and resolves over time. Care of these infants goes beyond the scope of this document.

Late Sequelae of Necrotizing Enterocolitis (NEC): There is a 10-22% incidence of strictures/intestinal stenosis in children experiencing NEC. These infants usually present with a partial bowel obstruction or with failure to grow adequately with a peak incidence of this complication at 2-8 weeks after the acute episode. Some children will be discharged with a surgical stoma site that requires proper skin care and monitoring for potential fluid and electrolyte imbalance with even mild gastrointestinal illness. Additionally, intestinal fistulas may occur. If a long segment bowel resection was necessary, short gut syndrome with attendant issues of malnutrition and growth failure, vitamin and mineral deficiencies (fat soluble vitamins, vitamin B12, zinc, calcium), or potentially late onset bacterial sepsis may require long term management.

Hernias: Inguinal and umbilical hernias occur more frequently in LBW infants than in full term infants. Along with screening for hernias as part of ongoing well child care, primary care providers should instruct the parents of premature infants in the signs and symptoms of hernias, especially an incarcerated inguinal hernia, and the differentiation between a hydrocele and an inguinal hernia. Guidelines on seeking medical attention should be reviewed with parents.

Rehospitalization: Rates of rehospitalization are greater for LBW infants than for the normal birth weight population, especially during the first year of life. The likelihood of readmission for the VLBW infant has been reported to be as high as 38%. After the first year rehospitalization rates fall to 10%. Surgical interventions for strabismus, otolaryngological procedures, and hernia repair are not uncommon. LBW infants/children have an increased number of rehospitalizations for pulmonary conditions such as reactive airway disease, respiratory syncytial virus (RSV) and other pulmonary infections. Respiratory

complications often decrease after two years of age. Other hospitalizations may occur for specific organ system abnormalities such as cardiac defects or central nervous system complications.

Dental Issues: Children born prematurely have a high prevalence of dental enamel hypoplasia (62% in VLBW children, 27% in LBW). In addition to the adverse effects of systemic illnesses during the neonatal period, deficiency of calcium and phosphorus in the neonatal period is directly related to enamel hypoplasia of the VLBW child. Local factors such as laryngoscopy and endotracheal intubation have also been implicated in the etiology of enamel hypoplasia.

Very preterm infants may have delays of tooth eruption, but by two years of age usually demonstrate a normal complement of teeth.

Osteopenia of Prematurity: During the last trimester there is a sixfold increase in fetal calcium and phosphorus accumulation. Osteopenia of prematurity may present clinically between the 6th and 12th postnatal week and is most commonly caused by inadequate mineral intake. Supplementaion of human breast milk or attention to mineral content of formula is indicated.

Risk factors for developing osteopenia of prematurity include total parenteral nutrition requirement for longer than 2 weeks, use of non-preemie formulas or non-fortified human milk in the hospital, use of soy formula, and drug-nutrient interactions such as steroids and diuretics impacting calcium, phosphorus, and vitamin D metabolism. The disease is usually subclinical and is often an incidental finding on radiographs which may show metaphyseal changes, osteopenia, and fractures. Additional findings may generally include growth failure, dental enamel hypoplasia, widely split sutures, craniotabes, and perhaps pathologic fractures. Laboratory workup reveals normal serum calcium, low to normal serum phosphorus, and elevated plasma alkaline phosphatase activity. Regular radiographic may assist with diagnosis and follow up.

NEURODEVELOPMENTAL OUTCOME -

MAJOR SEQUELAE OF LOW BIRTH WEIGHT

Cerebral Palsy: Cerebral palsy is the most common neurodevelopmental disability encountered in LBW infants. It ranges in occurrence from 20% in the smallest infants to 6-8% of children of 1500-2500 gram birth weight. By comparison, CP occurs in about 2/1000 (0.2%) live births, half to preterm and half to full term infants. In LBW infants, the spastic forms are predominant (diplegia, hemiplegia, and quadriplegia) although any form of cerebral palsy may be seen. Spastic diplegia, in particular, is strongly associated with prematurity with at least 2/3 of children with this disorder born before 37 weeks gestation. The presence of periventricular leukomalacia, especially extensive or with cyst formation as documented by CT scan or cranial ultrasound, is associated with spastic diplegia.

Mental Retardation: Mental retardation (standardized intelligence quotient or developmental quotient more than 2 standard deviations below the mean) may or may not be associated with microcephaly. A child with head circumference greater than 3 standard deviations below the mean is at very high risk. Mental retardation often occurs in combination with one or more of the other major disabling conditions listed here, especially cerebral palsy. Mental retardation is seen in 4-6% of LBW graduates at school age and the percentage rises as the birth weight falls.

Hearing Impairment: LBW infants are at increased risk for both neurosensory hearing loss and conductive hearing loss. Hearing impairment severe enough to require hearing aids and augmented communication (40-100 dB loss) occurs in 2-3% of LBW children and does not specifically affect the smallest infants. Higher risk for hearing impairment is present in children who experienced persistent pulmonary hypertension, ototoxic drugs, infections, perinatal asphyxia, and hyperbilirubinemia, among other causes. Additionally, chronic and recurrent otitis media are more common in preterm infants (20-30%) than in full term infants. BAER is the recommended test for NICUs. Otoacoustic emission screening is widely used in newborn nurseries as per universal

screening recommendations. Further hearing assessment is dependent on the risk factors present for hearing loss, findings of initial screening, and index of suspicion on the part of family or physician. (Hearing loss risk factors are listed in Appendix 3.)

Visual Impairment: Blindness is more prevalent (6%) in children with birth weights of less than 1000 grams, predominantly occurring as a sequela of retinopathy of prematurity (ROP). The incidence of ROP is small in the infant born beyond 28 weeks gestation or greater than 1500 grams birth weight. "Infants with a birth weight of less than 1500g or gestational age of 30 weeks or less and selected infants with a birth weight between 1500 and 2000g or gestational age of more than 30 weeks with an unstable clinical course, including those requiring cardiorespiratory support and who are believed by their attending pediatrician or neonatologist to be at high risk, should have retinal screening examinations to detect ROP." [14] Recommended timing is as follows: [14]

	Age at Initial Examination, wk	
Gestational Age at Birth, wk	Postmenstrual	Chronologic
24	31	7
25	31	6
26	31	5
27	31	4
28	32	4
29	33	4
30	34	4
31*	35	4
32*	36	4

*If necessary.

Follow up is as needed;[14] infants may need to be seen as often as weekly until full retinal vascularization occurs and to continue close ophthalmologic follow-up though the first year of life. The ophthalmologist will establish the initial follow-up schedule for these VLBW infants depending on their stage of ROP, and will determine their long term eyecare needs. Decreased visual acuity, myopia, strabismus, glaucoma, and ROP induced retinal complications occur more frequently, especially in the less than 1000 gram birth weight infant. Strabismus may be associated with the neuromotor disability of cerebral palsy. Myopia at school age is present in an estimated 30% of the smallest LBW survivors. Monitoring of eye alignment, red reflex, and acuity must be part of routine follow-up of the LBW infant. Visual and hearing impairments may coexist in a child, with prematurity being the leading cause of multisensory handicap in children.

Progressive Hydrocephalus: 20-30% of infants less than 1500 grams birth weight have evidence of intracranial hemorrhage and a small subgroup (3-5%) of these infants develop progressive ventriculomegaly requiring shunt placement. Progressive post-hemorrhagic hydrocephalus usually becomes clinically evident between 2-8 weeks postnatal age, however appearance during late infancy has been reported. Head growth out of proportion to any catch up growth in length and weight or genetic potential is an indication for referral for further evaluation.

Chronic Seizure Disorders: Neonatal seizures occur in up to 20% of low birth weight infants. The risk of infants with neonatal seizures developing recurrent non-febrile seizures requiring prolonged anticonvulsant therapy varies according to the etiology of the neonatal seizures, the number of days of seizure occurence, and the EEG pattern. Recurrent seizures usually present within eight months of birth.

NEURODEVELOPMENTAL OUTCOME – MINOR SEQUELAE OF LOW BIRTH WEIGHT

Cognitive: Despite mean IQ scores that fall in the average range, as a group LBW children score significantly lower than normal birth weight children on intelligence tests, even when corrected for socioeconomic factors. Rates of abnormal (IQ<68-70) and low normal or borderline (IQ 70-84) intelligence are significantly higher than among normal birth weight children. As with most outcomes in this population, prevalence of problems increases as birth weight decreases, with more than twice as many LBW children as normal birth weight children falling in the borderline range on IQ testing. Children in this group often require special education. Socioeconomic disadvantages may further exacerbate these difficulties.

Speech and Language: Communication skills are critical to academic learning and social adjustment. In the VLBW population, 15-20% of children with normal intelligence (IQ>84) have been reported to have a language disability.

Receptive and expressive language delays in toddler years and beyond, difficulties with vocabulary and word finding, and inferior performance in articulation and fluency have all been reported.

Neuromotor disorders: Although a majority of LBW infants fall within the normal range on neurologic exams, rates of neuromotor dysfunction are higher in this population including difficulties with postural control, balance and coordination, and poor quality of motor function, including difficulty in fine motor skills. Visual-motor and/or visual-perceptual dysfunction is present in about 20% of LBW infants.

Neurobehavioral Development: In early infancy, low birth weight infants demonstrate difficulties with visual and auditory orientation, state control (quiet-active status), and autonomic regulation. Preterm infants tend to fuss more, smile less, and are less soothable. Alterations in the parent-child interactions sometimes result. Differences in expressive behavior, social competence, and affect may persist. Researchers have demonstrated an increased risk of behavioral problems such as conduct disorder, hyperactivity, and attentional difficulties. Some children demonstrate a pattern of shyness, unassertiveness and withdrawn behavior. Even in adolescence, distractibility, irritability, low frustration tolerance, fears, disobedience, poor motivation, and sleep difficulties have been reported. There is an increasing prevalence of these problems with decreasing birth weight, as well as a higher incidence of these difficulties in males.

School function: It is very difficult to adequately predict or identify minor developmental and behavioral dysfunction before school entry. Compared to children of normal birth weight at school age, there is an increased incidence of mild learning disabilities and attention disorders. Selective impairments in areas such as arithmetic reasoning, reading comprehension, fine motor skills, spatial abilities, expressive language and memory impact school performance. These children experience lower levels of achievement in math, reading, and spelling. Up to half of VLBW children are receiving special education services. Some must learn to cope with lifelong disabilities.

NEURODEVELOPMENTAL EVALUATION:

How does the primary health care provider choose how and where to monitor and evaluate each LBW NICU graduate in his/her practice? Factors to consider are the number of perinatal, neonatal, and environmental risk factors present for the child and family, the child's size at birth and degree of prematurity, current family functioning, distance to various services, and third party payer requirements. The lower the birth weight and gestational age at birth, the higher the risk of adverse health or neurodevelopmental sequelae. An SGA infant is at greater risk for neurodevelopmental impairment than an AGA infant equally premature. Presence of perinatal risk factors (See Appendix 4) indicates higher risk for neonatal morbidity and the presence of neonatal morbidity translates into higher risk for developmental delays. Increasing numbers of environmental/family risk factors are associated with poorer developmental outcomes. Higher biologic risk combined with higher environmental/family risk factors warrants very close monitoring and potentially earlier intervention.

In the primary care provider's office, screening for growth, gross and fine motor development, cognitive and language abilities, and behavioral development have traditionally been a part of normal well child care. A single data point provides limited information about the ongoing growth and development of the child. Surveillance requires observation of developmental progress over time. There are several options for providing the special health and neurodevelopmental screening for high risk infants and children (See Appendix 5). Individual primary care providers may feel comfortable with many aspects of these assessments and have resources within their practice to provide them. Other aspects may require referral to other professionals and/or high risk infant follow-up programs.

Neurodevelopmental evaluations are available from tertiary care centers, multidisciplinary high risk infant follow-up clinics, and birth-to-three

developmental centers. For ages 3-5 years, local school districts also provide some of these services. For children 0-3 years old, "Birth-to-Three" services are available in some school districts. Some evaluation sites provide assessments by only one or two disciplines (as listed below). For infants and children with fewer risk factors and single areas of concern, these sites can provide satisfactory evaluations. Other children, especially the medically fragile infant, may benefit from a complete neurodevelopmental evaluation. Although often located in urban areas and requiring considerable travel for some families, tertiary care centers and multidisciplinary high risk infant follow-up clinics have specific expertise with this population and provide multi-faceted evaluations. Multidisciplinary high risk infant follow-up programs vary in the make-up of the multidisciplinary team. These programs are usually designed to provide assessment of the infant or child from several professional viewpoints and to present a coordinated and comprehensive set of recommendations for the child and family with facilitation of service provision.

Professionals that may be involved in providing evaluations for low birth weight NICU graduates include:

- Pediatric physical therapist (PT)
- Pediatric occupational therapist (OT)
- Pediatric speech and language pathologist (SLP)
- Registered nurse with high risk infant experience (RN)
- Registered dietician with high risk infant experience (RD)
- Developmental pediatrician (pediatrician with neurodevelopmental expertise)
- Pediatric clinical psychologist
- Pediatric audiologist
- Social worker
- Early childhood educator
- Family Resources Coordinator (for children ages birth to three years)

Each multidisciplinary site provides a combination of some of these specialists on site to provide a comprehensive evaluation and recommendations. In the current managed care environment, the primary care provider reviews the recommendations and follows up with lab work and therapy referrals as indicated.

FAMILY

Family Issues: Having a premature birth and the subsequent hospitalization of the infant puts parents into a state of heightened stress and leaves them with years of anxiety. Even the parents of relatively healthy larger preemies report feeling unresolved grief for years. Parents may experience an emotional roller coaster ride in the first weeks to year or more of their LBW infant's life.[12] This stress and the extra time required by the premature infant can have negative consequences for siblings, maintaining employment, and the parents' relationship. The hospital discharge of the infant creates a whole new crisis for parents, which is often unrecognized by professionals in and outside the hospital. Parents often feel very isolated as they take on the care of their infant and, if they were told that their baby is now just like any full-term infant, they feel guilty for not being able to elicit full-term social, feeding, and motor behavior from their infant.

There is often a need for weekly office visits during the first weeks or months post hospital discharge for the family and LBW infant. To complement the primary care provider's efforts and reduce rehospitalization during this transition period, a specially trained visiting nurse can also weigh the infant at home and help parents with feeding techniques, infant cues, thermoregulation, and infection prevention. Visiting nurses who are familiar with this population can provide supplementary information to parents on subjects like premature infants' sleep-wake cycles, parent/infant communication, attachment, handling techniques, siblings, safety, and community resources.

Primary care providers should evaluate the possible residual impact of low birth weight infants' early illnesses and hospitalizations on parental attitudes and caregiving practices. Mothers, in particular, may continue to have intense emotional responses to this experience that may influence a style of parenting. A heightened

sense of protectiveness and perception of the child as vulnerable may be related to the perception of the child as "special for having survived a very difficult experience". This is often accompanied by residual concerns for the child's health. Of particular concern in the preschool years, are issues surrounding discipline and limit setting. Parental guidance is sometimes needed in setting appropriate limits while promoting autonomy. Contact with national and local organizations may be helpful.

Doubly-vulnerable infants: Preterm and low birth weight infants who are at risk for developmental delay and impaired health secondary to both medical conditions and to their family and living conditions are referred to as doubly-vulnerable. Family situations that can contribute to poorer developmental outcomes include:

- mother with less than high school education
- prenatal substance exposure and continued substance abuse in the family
- poverty
- parents under 20 years of age
- parent with lack of social support or socially isolated
- history of domestic violence

Cultural Competence: Preterm infants born to families outside the predominant culture may experience decreased access (actual and perceived) to health care and to the activities and resources enjoyed by other families. Decreased access can contribute to delayed development and poor school performance. Most health care facilities are run by and staffed by persons of the predominant culture. If the large and small effects of cultural differences are not recognized throughout the entire health care and early intervention system, erroneous conclusions about the child and family can jeopardize meaningful work with them.

Cultural Competence has been defined as being "able to conduct one's professional work in a way that is congruent with the behavior and expectations that members of a distinctive culture recognize as appropriate among themselves." It includes:

- an awareness of one's own cultural limitations
- openness, appreciation and respect for cultural differences
- a view of intercultural interactions as learning opportunities
- the abiltiy to use cultural resources in interventions
- an acknowledgement of the integrity and value of all cultures[13]

A guideline for working with a family of another culture is to work with them as individuals, rather than assuming that they have the same beliefs as others of the culture. Building rapport through respectful communication is imperative in a therapeutic relationship.