

Low Birth Weight Neonatal Intensive Care Unit Graduate

CRITICAL ELEMENTS

OF CARE

A Washington State Consensus Project

Funded by:

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Coordinated by:



**University of Washington
Center on Human Development and Disability, Seattle, WA**



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Critical Elements of Care (CEC) are designed to consider health care issues for children who have selected health risks or conditions requiring more than standard well child care, potentially from birth through adulthood. This particular CEC addresses the special health care needs of preterm low birth weight infants who have required neonatal intensive care after birth. The intent of the CEC is to educate and support health care providers, parents, third-party payers, and policy makers interested in caring for low birth weight infants and children. All are encouraged to use this document in planning services for these children.

Neonatal intensive care units provide services to infants with a wide range of life-threatening conditions. This CEC does not attempt to cover all of these conditions. It has been purposely limited to the post-NICU care of infants who: 1) were preterm and/or low birth weight (≤ 2500 grams at birth), 2) experienced the usual complications of prematurity and low birth weight, and 3) were discharged home in relatively healthy condition. Infants with serious, on-going health problems at hospital discharge need additional special care not covered by this document.

This CEC provides information and recommendations for monitoring, management and referrals for the health and neurodevelopmental conditions for which the healthy preterm low birth weight infant is at higher risk. At the same time, it is not possible to cover all the information relative to these conditions. The references and resources section of this document contains a **“further readings”** list which will help expand on diagnostic and management issues for the more common conditions present in this population.

A consensus process was utilized to develop the scope of information provided within this CEC. The consensus team was multidisciplinary with state-wide representation involving primary and tertiary care providers, parents, and a health plan representative.

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Individual variations in the condition of the patient, status of patient and family, and the response to treatment, as well as other circumstances, mean that the optimal treatment outcome for some patients may be obtained from practices other than those recommended in this document.

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This document and companion materials are available on the:

Medical Home Leadership Website at <http://www.medicalhome.org>

Link to specific materials: http://www.medicalhome.org/diagnoses/lbw_cg_gc.cfm

- [Low Birth Weight \(LBW\) NICU Graduate](#)
- [Extremely Low Birth Weight NICU Graduate Supplement to the CEC on LBW](#)
- Companion parent materials available:
 - [“Watching Your Low Birth Weight Child Grow – Tips for Parents”](#) (booklet)
 - [“Was Your Baby Born Early? Was Your Baby Born Small?”](#) (brochure)

Additional Critical Elements of Care currently available:

Center for Children with Special Needs <http://www.cshcn.org> (click on Resources)

- Sickle Cell Anemia
- Duchene Muscular Dystrophy
- Cleft Lip and Palate
- Cystic Fibrosis
- Juvenile Rheumatoid Arthritis
- Cerebral Palsy

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INTRODUCTION AND BACKGROUND

This set of guidelines is designed to assist the primary care provider in caring for the infant and child who weighed 2500 grams or less at birth and is to be utilized in conjunction with *AAP Recommendations for Preventive Pediatric Health Care* (see Appendix 1). Primary care providers are encouraged to share this CEC document with others involved in the care of children with a history of low birth weight or prematurity. Primary care providers will find it useful to become familiar with local community resources and phone numbers, such as public health offices and family resources coordinators (see Appendix 6).

This consensus-based document is intended as a guideline and is not intended to replace sound clinical judgment or individualized consultation with specialists regarding patient care needs.

The scope of this document is confined to the post-hospital care of the low birth weight infant *without* serious medical complications or congenital defects. The special care required by infants discharged to the community with moderate to severe organ system disorders will not be found in this document. Further readings on diagnosis and management of specific disorders common in the low birth weight NICU graduate can be found at the end of this document.

How to use this document

The *Critical Elements of Care for the LBW NICU Graduate* consists of four parts:

- I. Health and Neurodevelopmental Supervision Grid for the LBW NICU Graduate - designed as a quick reference and worksheet; *greater detail is found in sections II and III*
- II. Critical Elements of Care by Ages - detailing examination, management, anticipatory guidance, and potential interventions for the child at each age
- III. Health and Neurodevelopmental Supervision - containing background information
- IV. References and Further Readings

The Supervision Grid may be photocopied. **For effective use**, it is recommended that a copy of the

Supervision Grid be placed in the PCP's medical record of each LBW NICU graduate. The Supervision Grid is modeled on the AAP Recommendations for Preventive Pediatric Health Care and designed to be used along with the AAP Recommendations.

POPULATION

Approximately 309,000 low birth weight (LBW) infants (≤ 2500 grams) are born annually in the United States. This represents 7.6% of total U.S. births in 2000.¹ LBW infants are a heterogeneous group representing term infants with growth retardation/subnormal weight, as well as infants born preterm (< 37 weeks gestation) with or without growth failure. Low birth weight births are the major underlying cause of infant mortality and childhood morbidity. Increased survival of this population over the last 30 years has resulted in an increased prevalence of these vulnerable infants in the general population. It is necessary for physicians and other primary health care providers to be aware of the many real and potential problems seen in this group of children and their families throughout their life span. Coordination of care for these infants requires attention to the health, development, and social milieu of the child and family.

BACKGROUND

Currently, most infants born at 24 weeks gestational age or greater survive. A majority of low birth weight infants become normal, healthy children and adults. One must remember to evaluate each child as an individual as many will escape the sequelae of prematurity. However, as a group, these children have a higher rate of suboptimal growth, adverse health conditions, and neurodevelopmental problems than children born at term. The number and severity of adverse outcomes generally increase with decreasing birth weight. There are a significant residua of health and growth concerns that must be monitored, especially during the first year of life but continuing through adolescence. Identified chronic health issues require continued management.

Basic monitoring of the LBW survivor includes special attention to: neuromotor development in the first year of life, language and cognitive development in the second and third years of life, school readiness at 4-5 years of age, and academic achievement during the early school years through adolescence. Attention to social competence and family functioning at each age is important.

Examples of Developmental Concerns for LBW Infants By Age

Birth to 1 Year

- Neurodevelopmental abnormalities
 - Cerebral Palsy
- Sensory abnormalities
 - Vision loss, strabismus
 - Hearing loss
- Neurobehavioral organization difficulties

2-4 Years

- Speech and language delay/disorders
- Cognitive delays
- Social emotional developmental difficulties
- Mild sensory abnormalities (vision/hearing/tactile defensiveness, etc.)

4-5 Years

- School readiness issues and/or cognitive delays
- Fine Motor incoordination
- Clumsiness, gross motor 'immaturity'
- Social competence/behavioral immaturity

Early Elementary Years:

- Learning disabilities and/or cognitive delays
- Visual motor difficulties
- Attention disorders
- Social competence difficulties

very low birth weight (VLBW, ≤ 1500 grams birth weight) survivors and is even greater in the extremely low birth weight population (ELBW, ≤ 1000 grams birth weight). Minor neurodevelopmental and neurobehavioral sequelae may become major impediments to academic and social success and may carry over into difficulties in adult life skills. Despite some associations with specific complications in the neonatal period, individual developmental outcome remains very difficult to predict, and often two infants with similar hospital courses develop quite differently.

It is important to note that some of the effects of low birth weight can be attenuated or reversed. Intensive enrichment programs with medical services, early intervention, and family and parenting support have improved developmental outcomes for LBW children.

Corrected age: There is general consensus that the age of the child be corrected for prematurity **at least until the child has reached three years of age**. Corrected age is calculated from the infant's *due date rather than from the date of birth*. (The common methods for determining due date are counting 40 weeks from the first day of the mother's last menstrual period, from early fetal ultrasound or from exam at birth.)

For example: A child born at 32 weeks gestation rather than at 40 weeks is 8 weeks early (40wk - 32wk = 8wk) or 56 days early (8 wk x 7 day/wk = 56 days). Corrected age for this child is calculated by subtracting 56 days from his/her chronologic age.

**I. HEALTH AND NEURODEVELOPMENTAL SUPERVISION GRID -
LOW BIRTH WEIGHT NICU GRADUATE**

HEALTH & NEURODEVELOPMENTAL SUPERVISION GRID: LOW BIRTH WEIGHT																			
See CEC Sections II & III for more specific information	NICU	Infancy (Corrected ages through 2-3 yo)								Early Childhood				Late Childhood	Adolescence				
Medical Evaluation	D/C	1 mo	2 mo	3 mo	4 mo	5 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	3 y	4 y	5-13 y per AAP schedule	13-21 y Annual			
NICU Discharge Plan ¹	•																		
Interim History	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			
Growth (L/HT, WT, OFC) ²	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			
Nutrition/Feeding ³	•	S	S	S	S	S	S	S	S	S	S	S	S	S	S	S			
Vision ⁴	O	S	S	S	S	S	S	S	S	S	S	S	•	•	• 5 Y	• 10Y	• 12Y	• 15 Y	• 18 Y
Hearing ⁵	O	—	—	—	S	S	S	S	S	S	S	S	•	•	• 5 Y	• 10Y	• 12Y	• 15 Y	• 18 Y
Special Health Concerns ⁶	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			
Development/Behavior Assessment ⁷																			
Temperament/rhythmicity ⁸	S	S	S	S	S	S	S	S	S	S	S	S	S	S	S	S			
Sensorimotor ⁹	O	S	S	S	—	—	—	O	—	O	—	O	S	S	S	S	S		
Language ¹⁰								S	S	S	S	—	O	—	S	S	S		
Cognitive ¹¹								S	S	S	S	S	—	O	—	S/O	S/O		
Social/Adaptive Behaviors ¹²		S	S	S	S	S	S	S	S	S	S	S	—	O	—	S/O	S/O		
School Performance ⁷															S/O	S/O			
Family Support ^{1, 13}	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			
<p>Assure compliance with the American Academy of Pediatrics "Recommendations for Preventive Pediatric Health Care."</p> <ul style="list-style-type: none"> • = To be performed in primary care setting; referral as indicated. O = Objective; standardized testing; referral to appropriate specialist(s) as indicated. S = Subjective; by history or observation. O — = Assessment range with preferred age (symbol). ■ = Emphasized developmental domain. 																			
<ol style="list-style-type: none"> See AAP Policy Statement. "The Role of the Primary Care Pediatrician in the Management of High Risk Newborn Infants"^{reference 2}; "Excerpts from Family Centered Care"^{reference 3}; and "Hospital Discharge of the High Risk Neonate"^{reference 4} Record on standard growth charts or on premature infant grids using corrected age. Referral to nutritionist, lactation consultant, feeding specialist or GI specialist as indicated. Examination by an ophthalmologist prior to NICU discharge when indicated and again as recommended by ophthalmologist. Screening BAER prior to NICU discharge. If not done in NICU, refer for BAER within 3 months. If failed, repeat within 3 months. Closely monitor for hearing loss (conductive or progressive neurosensory hearing loss may occur later); high risk groups should be retested every 6 mos. until 3 y.o. High Risk = Family history of early onset hearing loss, persistent pulmonary hypertension as newborn, s/p TORCH infection, s/p meningitis, hyperbilirubinemia requiring exchange transfusion. Consultation with pediatric subspecialists as indicated. Consider referral to early intervention program from birth to 36 months; transition to public school preschool program at 36 months as indicated. Age 6-18, refer for psychometric testing through school district or psychologist as indicated. Subjective assessment of child's temperament and daily rhythms at each visit. Standardized movement assessment recommended at approximately 4 to 6 months, 8 to 12 months, and 15 to 18 months corrected age. Standardized communication assessment recommended at approximately 18 to 36 months corrected age. Standardized cognitive assessment recommended at approximately 36 to 48 months of age. Subjective assessment of social/adaptive behaviors at all visits. Standardized assessment at 36 to 48 months of age. See "Excerpts from Family Centered Care..."^{reference 3} Refer to appropriate local family support services as indicated. Coordinate referrals with insurance providers to maximize coverage for services. <p>If a child enters care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.</p>																			

II. CRITICAL ELEMENTS OF CARE BY AGE OF CHILD

II Critical Elements of Care by Age of Child

Nursery Discharge Plan and Establishing Primary Care

Area Of Focus	Assessment	Interventions Referral Resources	Anticipatory Guidance
Medical Evaluation	<ul style="list-style-type: none"> - Comprehensive physical and neurodevelopmental examinations prior to discharge 	<ul style="list-style-type: none"> - Send reports promptly to all appropriate providers - Initiate referral to appropriate service providers 	<ul style="list-style-type: none"> - Transition into outpatient services as needed - Review: <ul style="list-style-type: none"> • Signs and symptoms requiring urgent medical attention • How to access urgent or emergency care/CPR training • Daycare & infection exposure issues • Provision of safe environment (car seat, supine sleeping) • Support of developmental & behavioral organization
Interim History	<ul style="list-style-type: none"> - Formulate discharge plan with family • Attend to AAP recommended health care supervision guidelines (Appendix 1) • Comprehensive D/C summary and plan completed (Appendix 2) 	<ul style="list-style-type: none"> - Provide parent/caregiver education: <ul style="list-style-type: none"> • Premature infant state control and behavior issues • Basic parenting/daily infant care • Special medical needs and medications - Schedule 1st PCP appointment - Discharge with needed medications 	
Growth	<ul style="list-style-type: none"> - Review current growth: <ul style="list-style-type: none"> • Target 20-30 gm/day gain • Assess weight, length & OFC at discharge 		<ul style="list-style-type: none"> - Breast feeding (if desired) may not be fully established, extra monitoring with support are often needed - Guidelines for weight rechecks: <ul style="list-style-type: none"> • PCP office • WIC/PHN
Nutrition/ Feeding	<ul style="list-style-type: none"> - Review nutritional intake <ul style="list-style-type: none"> • Supplemental calories • Special formula or fortifiers • Breast feeding status • Oral/motor function • Consider vitamin & mineral supplementation needs 	<ul style="list-style-type: none"> - Review: <ul style="list-style-type: none"> • Parent's comfort & ability to feed infant • Understanding of formula preparation, feeding volumes & preparation • Infant feeding behaviors • Positioning techniques for feedings Referral Resources: <ul style="list-style-type: none"> • Lactation specialists • Nutritionist • Feeding specialist • GI specialist • WIC • PHN 	<ul style="list-style-type: none"> - WIC programs do not correct age and may introduce solids, whole milk, etc. prematurely for infants born VLBW. - WIC should be informed of special needs of infant.
Vision	<ul style="list-style-type: none"> - Ophthalmologic exam for ROP and other conditions prior to D/C or schedule as outpatient for any infant ≤ 1500 gm BW or ≤ 30 weeks GA - Selected infants with a birthweight 1500 - 2000 grams or > 30 wk GA with unstable clinical course (see NICU d/c summary) 	<ul style="list-style-type: none"> - Schedule outpatient ophthalmology appointment (with pediatric ophthal. familiar with ROP) 	<ul style="list-style-type: none"> - Sequelae of ROP: <ul style="list-style-type: none"> • Risks for amblyopia, strabismus & acuity abnormalities if infant had any grade ROP • More severe ROP has more complications (e.g. retinal detachment) - Review normal visual developmental expectations
Hearing	<ul style="list-style-type: none"> - Audiology exam prior to discharge - Assess risk of hearing impairment (see Appendix 3) 	<ul style="list-style-type: none"> - If hearing not tested prior to discharge or if not passed bilaterally, infant should be tested within 1-3 months of age - Referral Resource: <ul style="list-style-type: none"> • Pediatric Audiologist 	<ul style="list-style-type: none"> - Educate parents about hearing development and risk factors for delay present (if any)
Special Health Concerns	<ul style="list-style-type: none"> - Consultation reports from NICU to PCP/other care providers - Anemia of prematurity - Assess for special health concerns <ul style="list-style-type: none"> • S/P NEC • RAD/pulmonary function • GERD • Hernias • SIDS risks • Neurologic concerns - seizures, hydrocephalus • Kidney stones • Other 	<ul style="list-style-type: none"> - Schedule needed outpatient care and follow-up with sub-specialists - Review need for: <ul style="list-style-type: none"> • Oxygen • Medications • Monitors • Vitamin &/or mineral supplementation • Specific preventative measures for respiratory exposure 	<ul style="list-style-type: none"> - Communicate special health needs with parents <ul style="list-style-type: none"> • Provide specialists' names and numbers • Avoid exposure to respiratory irritants, such as cigarette smoke

II Critical Elements of Care by Age of Child

Nursery Discharge Plan and Establishing Primary Care

Area Of Focus	Assessment	Interventions Referral Resources	Anticipatory Guidance																	
Developmental Behavioral Assessment	<ul style="list-style-type: none"> - Assessment of infant's behavioral and state control 	<ul style="list-style-type: none"> - Teach parents/caregivers to read infant cues, support infant self-regulation, understand integration of systems, modify environment - Developmental specialist: <ul style="list-style-type: none"> • OT • PT • Educator 	<ul style="list-style-type: none"> - LBW infants as a group have more difficulties with quiet-active status (state control) and interactive feedback resulting in difficulties in sleeping, feeding and crying - LBW infants may need extra attention to: <ul style="list-style-type: none"> • Environment (decreasing number and intensity of stimuli) • Positioning 																	
Temperament/ Rhythmicity				Sensory/ Motor	<ul style="list-style-type: none"> - Examination prior to discharge to assess neuromotor and behavioral baseline (e.g. Brazelton Neonatal Behavioral Scale) 	<ul style="list-style-type: none"> - Make recommendations based on infant's history and developmental evaluation - Referral Resources: <ul style="list-style-type: none"> • OT • PT • High risk infant follow up clinic • Neurodevelopmental center (Appendix 6) 	<ul style="list-style-type: none"> - Review infant positioning and handling - Review need for developmental monitoring and assessment. - Developmental progress should be reviewed by corrected, not chronologic age 	Language				Cognitive				Social Adaptive				Family Support
Sensory/ Motor	<ul style="list-style-type: none"> - Examination prior to discharge to assess neuromotor and behavioral baseline (e.g. Brazelton Neonatal Behavioral Scale) 	<ul style="list-style-type: none"> - Make recommendations based on infant's history and developmental evaluation - Referral Resources: <ul style="list-style-type: none"> • OT • PT • High risk infant follow up clinic • Neurodevelopmental center (Appendix 6) 	<ul style="list-style-type: none"> - Review infant positioning and handling - Review need for developmental monitoring and assessment. - Developmental progress should be reviewed by corrected, not chronologic age 																	
Language																				
Cognitive																				
Social Adaptive																				
Family Support	<ul style="list-style-type: none"> - Assessment of family needs - Individualized plan of support 	<ul style="list-style-type: none"> - Schedule 1st PCP appointment usually 1-2 weeks post discharge - Schedule post D/C home visit (nursing if needed & available) - Resources: <ul style="list-style-type: none"> • SW • FRC (Appendix 6) • CPS • PHN - Coordinate referrals with insurance providers to maximize coverage for services - Reading materials (see References and further reading section) 	<ul style="list-style-type: none"> - Discharge brings new stressors to the home: <ul style="list-style-type: none"> • Infant's health needs • Reestablishment of parental roles at home • Sibling issues 																	

II Critical Elements of Care by Age of Child

1 Month to 1 Year - Infancy

Area Of Focus	Assessment	Interventions Referral Resources	Anticipatory Guidance
Medical Evaluation	<ul style="list-style-type: none"> - History & physical examination by systems - Continuity of comprehensive care 	<ul style="list-style-type: none"> - Case management, care coord. - Follow AAP recommended guidelines for health supervision 	
Interim History	<ul style="list-style-type: none"> - Identify health concerns 	<ul style="list-style-type: none"> - Immunization by chronologic age schedule (not corrected age) on routine immunization schedule 	
Growth	<ul style="list-style-type: none"> - Growth measurement Lgth, Wt, OFC at each visit (Plot growth on standardized grid by corrected age) <ul style="list-style-type: none"> • Goal 20-30 gm/day wt. gain for 1st 6 mos. 	<ul style="list-style-type: none"> - If inadequate growth: <ul style="list-style-type: none"> • Formal assessment of calorie intake • Assess for medical cause 	<ul style="list-style-type: none"> - Review catch up growth patterns commonly seen in AGA & SGA infants
Nutrition/ Feeding	<ul style="list-style-type: none"> - Review nutritional intake: <ul style="list-style-type: none"> • Breast feeding • Formula preparation • Oral motor skills • Feeding time issues - Assess for developmental appropriateness of feeding skills and readiness to start solids - Fluoride supplementation as indicated (0.25mg/da) beginning at 6 months (corrected age) <ul style="list-style-type: none"> • formula prepared from unfluoridated tap water or bottled water - Multivitamin supplement until consuming at least 24 oz/day - Iron supplementation if not receiving a formula containing iron 	<ul style="list-style-type: none"> - Review feeding mechanics - Referral Resources: <ul style="list-style-type: none"> • Lactation consult • Nutritionist • Feeding specialist/Feeding Clinic • GI specialist • PHN 	<ul style="list-style-type: none"> - Advance feeding when developmentally and motorically ready by corrected age <ul style="list-style-type: none"> • Solid intro 4-6 mos. C.A. • Breast milk and/or formula through 1st year corrected age • Finger foods • Table foods
Vision	<ul style="list-style-type: none"> - Monitor vision, with special consideration for signs of visual impairment and strabismus - Assess visual tracking - Continue vision evaluations for ROP, nearsightedness, and strabismus as determined by ophthalmologist 	<ul style="list-style-type: none"> - Referral to Ophthalmologist as indicated 	<ul style="list-style-type: none"> - Monitor for: <ul style="list-style-type: none"> • Eye crossing or concerns about vision - Normal visual development <ul style="list-style-type: none"> • Binocular vision by 4 mos. corrected age (eyes should not cross except for near vision)
Hearing	<ul style="list-style-type: none"> - Pediatric audiological evaluation within first 3 months if has not been done previously or if infant failed initial test - Check for orienting bilaterally starting at 4-6 months corrected age - Observe for delayed onset hearing loss (See Appendix 3) 	<ul style="list-style-type: none"> - Referral Resources: <ul style="list-style-type: none"> • Pediatric Audiology 	<ul style="list-style-type: none"> - Child with hearing loss may "coo" at normal age & then not progress (i.e., consonant sounds at 6-7 mos CA) - Children with hearing loss are very visually alert. May mistake visual orienting for sound perception if not very careful in the presentation of the sound stimulus
Special Health Concerns	<ul style="list-style-type: none"> - History & physical by systems - R/O anemia (at 2 months chronologic) - R/O Vit. D deficiency (Rickets risks may present as early as 6-12th postnatal week) - Assess dentition: <ul style="list-style-type: none"> • Infant may be at risk for enamel hypoplasia due to lack of mineralization/nutrition, medication, intubation - Assess for common health issues in the preterm population: <ul style="list-style-type: none"> • S/P NEC • RAD/pulmonary function • GERD • Hernias • SIDS risk • Neurologic concerns - seizures, hydrocephalus • Kidney stones • Infections 	<ul style="list-style-type: none"> - Laboratory work up; iron supplementation as needed - Pediatric dentist - Parent teaching teeth development care/hygiene and protection - Care coord. with consulting specialist, refer to specialists needed 	<ul style="list-style-type: none"> - Review as needed: <ul style="list-style-type: none"> • Infection exposure & control • Daycare issues & options • Potential long term/late complications of special health issues (e.g. post NEC vitamins & mineral deficiencies, post NEC late GI obstruction, anemia etc.) • Avoid exposure to cigarette smoke and other environmental respiratory irritants

II Critical Elements of Care by Age of Child

1 Month to 1 Year - Infancy

Area Of Focus	Assessment	Interventions Referral Resources	Anticipatory Guidance
Developmental Behavioral Assessment	<ul style="list-style-type: none"> - History from caregiver regarding behavioral organization/self regulation 	<ul style="list-style-type: none"> - Continue parental education and support. How to read behavioral messages, how to support self regulation (consider handouts/written information & booklets) (see * below) 	<ul style="list-style-type: none"> - Premature infants tend to fuss more & be more easily overwhelmed
Temperament/ Rhythmicity	<ul style="list-style-type: none"> - Review/assess <ul style="list-style-type: none"> • Sleep patterns • Feeding patterns • Temperament issues • Parent/child interactions 	<ul style="list-style-type: none"> - Referral resources: <ul style="list-style-type: none"> • OT/PT • Health Educator • PHN • High risk infant follow-up program 	<ul style="list-style-type: none"> - Review infant cues & parenting responses
Sensory/ Motor	<ul style="list-style-type: none"> - Expanded physical exam for muscle tone, infant reflexes and motor function, motor milestones and movement quality (in office or refer) <ul style="list-style-type: none"> • Exam based on corrected age • Serial assessments • Early signs of neuromotor dysfunction/abnormalities often seen during first year of life 	<ul style="list-style-type: none"> - Referral to multidisciplinary neurodevelopmental assessment program if: <ul style="list-style-type: none"> • Abnormalities in tone, posture, or movement are suspected • Delayed milestones (by corrected age) are noted • Other atypical development is noted 	<ul style="list-style-type: none"> - Developmental progress based on corrected age - Avoid walker, saucers, and johnny jump-up use - Encourage supervised play in prone
Language	<ul style="list-style-type: none"> - History and observation of typically emerging language milestones - Monitor hearing responses <ul style="list-style-type: none"> • 4-6 mos. orienting to sound 	<ul style="list-style-type: none"> - Review language stimulation activities - Referral Resource: <ul style="list-style-type: none"> • Audiology 	<ul style="list-style-type: none"> - Parents should talk, read and sing to and with infant - Reciprocal interaction - Review language milestones
Cognitive	<ul style="list-style-type: none"> - Monitor development milestones <ul style="list-style-type: none"> • Language development is best early indicator of cognition • Administer development screening tests • Serial assessments of developmental progress • Assess environmental/infant stimulation issues 	<ul style="list-style-type: none"> - Review infant stimulation activities and home suggestions - Refer to multidisciplinary assessment or High Risk Infant Follow-up Program if delayed or atypical development is suspected - Home program or EI program as indicated (Birth to Three referral/Family Resources Coordinator) 	
Social Adaptive	<ul style="list-style-type: none"> - Assess infant's social interaction and coping mechanisms 		<ul style="list-style-type: none"> - Developmental expectations based on corrected age
Family Support	<ul style="list-style-type: none"> - Throughout the first year, monitor parent and family stress and coping, as well as understanding of appropriate infant development and behavior based on corrected age - Assess family's comfort with child and understanding of health issues, if present. 	<ul style="list-style-type: none"> - Consider referral to: <ul style="list-style-type: none"> • A community health nurse for home and family assessment and recommendations • Help families access available community resources, including parent/family support services and parenting classes • FRC referral (Appendix 6) • SW referral - Coordinate referrals with insurance providers to maximize coverage for services - Refer to literature resources and organizations for specific disorders (e.g., POP) 	<ul style="list-style-type: none"> - Families may receive support from communication with primary care provider and support services provided in the community

* e.g. *Homecoming for Babies After the Intensive Care Nursery. A Guide for Parent in Supporting Their Baby's Early Development.*

Hanson, M.J. and Vandenberg, K.A.

II Critical Elements of Care by Age of Child

Age 1 to 5 Years - Early Childhood

Area Of Focus	Assessment	Interventions Referral Resources	Anticipatory Guidance
Medical Evaluation	<ul style="list-style-type: none"> - Routine assessment 		<ul style="list-style-type: none"> - Most LBW NICU graduates do not develop adverse outcomes for which they are at higher risk (avoid "vulnerable child" syndrome)
Interim History			
Growth	<ul style="list-style-type: none"> - Measure height, weight, and head circumference at each visit and record until at least 2 years corrected age 	<ul style="list-style-type: none"> - If growth decelerates and child drops across a channel line on the growth chart: <ul style="list-style-type: none"> • Review for potential onset of illness causing growth deceleration and treat as indicated 	<ul style="list-style-type: none"> - Several patterns of catch up growth may be seen with some former NICU graduates, showing continued catch up in early elementary years
Nutrition/ Feeding	<ul style="list-style-type: none"> - Obtain feeding and nutrition history, assess for deviations from normal feeding pattern - Assess oromotor function and swallowing skills - Review calorie adequacy for catch up growth Review drug - nutrient interaction 	<ul style="list-style-type: none"> • Have parent take a 3 day food history • Consider referral to a pediatric nutritionist to review calorie adequacy and suggest methods of increasing caloric intake if needed - Referral as indicated to: <ul style="list-style-type: none"> • Feeding specialist (SLP, OT) • GI specialist • WIC/Health Department 	<ul style="list-style-type: none"> - Avoid lowfat milk before 2 years of age
Vision	<ul style="list-style-type: none"> - Assess per well child practice guidelines - Monitor eye alignment, red reflex, and acuity at each visit 	<ul style="list-style-type: none"> - Referral to ophthalmologist for strabismus, tearing, or acuity concern by exam or parent report - Referral to programs for visually impaired where indicated 	<ul style="list-style-type: none"> - If there was any evidence of ROP in the nursery, ophthalmology exams are recommended at one year corrected age and at school entry, or as requested by ophthalmologist (Due to increased risk of visual acuity abnormality or strabismus with any ROP history) - Virtually no retinal detachment & little retinal scarring is described in preterm infants >1500 gm BW
Hearing	<ul style="list-style-type: none"> - Monitor for conductive and/or sensorineural hearing loss at each visit - At ages 3 and 4 years perform audiology screen in office (assess per well-child practice guidelines) - Observe for delayed onset hearing loss (see Appendix 3) 	<ul style="list-style-type: none"> - Refer to Audiologist as indicated by exam, parent concerns or poor language development - ENT referral for documented hearing impairment - Amplification as indicated - Augmentative communication as indicated 	<ul style="list-style-type: none"> - Articulation difficulties may be the only presentation of a partial hearing loss - Children with hearing loss are very visually alert. One can mistake visual orienting for orienting to a sound stimulus if not careful in the stimulus presentation
Special Health Concerns	<ul style="list-style-type: none"> - Assess: <ul style="list-style-type: none"> • Dentition and reinforce good dental hygiene. • Monitor dental enamel hypoplasia • if S/P NEC - review for fat soluble vitamin & mineral adequacy & vitamin B12 • Reactive airway disease & abnormal pulmonary function • GERD - Monitor for late occurrence of feeding refusal secondary to occult reflux. Pay close attention to nutritional status • Hernias • Hydrocephalus, seizure disorder • Cerebral Palsy - hemiplegia, milder spastic diplegia, extrapyramidal CP, transient dystonia resolution may become apparent in the 1-2 yr. child 	<ul style="list-style-type: none"> - Dental referral as indicated - Medical consultation with pediatric subspecialist as indicated 	<ul style="list-style-type: none"> - Recommend pediatric dentist appointment in 3rd year of life or sooner for concerns - Continue to avoid exposure to airway irritants such as cigarette smoke

II Critical Elements of Care by Age of Child

Age 1 to 5 Years - Early Childhood

AREA OF FOCUS	ASSESSMENT	INTERVENTIONS REFERRAL RESOURCES	ANTICIPATORY GUIDANCE
Developmental Behavioral Assessment	<ul style="list-style-type: none"> - Subjective assessment at each visit. Ask about parental perception & concerns 	<ul style="list-style-type: none"> - Parenting information and behavior management skills - Refer to parenting classes as needed 	<ul style="list-style-type: none"> - May see impulsivity, overactivity, irritability etc. that may be early signs of ADHD. Note: Majority of LBW graduates do not have ADHD
Temperament/ Rhythmicity			
Sensory/ Motor	<ul style="list-style-type: none"> - Ask about parental perception of development at each visit, survey critical developmental milestones - Administer appropriate developmental screening tests at regular intervals (in office or refer) - Assess late sensorimotor development between 12 and 18 months of age (corrected) with standardized assessment test 	<ul style="list-style-type: none"> - Refer to a pediatric physical or occupational therapist or multidisciplinary team if concerned about atypical movement patters or delayed milestones 	<ul style="list-style-type: none"> - 20% of LBW infants have visual motor perceptual dysfunction - Increased incidence of difficulties with postural control, balance & motor coordination (e.g. tremulous involuntary hand movements) - Increased incidence of CP <ul style="list-style-type: none"> • 20% in smallest infants • 6-8% in the 1500-2500 gm BW infants
Language	<ul style="list-style-type: none"> - Ask about parental perception of development at each visit, survey critical developmental milestones. - Administer appropriate developmental screening tests at regular intervals (in office or refer) - Assess early language development between 18 and 30 months of age with standardized assessment tool - Monitor articulation and fluency 	<ul style="list-style-type: none"> - Hearing assessment if language is delayed - Consider referral to a pediatric communication disorders specialist if speech and/or language development appear delayed or atypical - For therapeutic intervention in any of the above areas of development: <ul style="list-style-type: none"> • 12-36 months of age - refer to an early intervention program or birth to three program with the desired therapies available • 33-60 months of age - refer to the local school district for a developmental preschool. (Children may not be eligible for enrollment in a school program until 36 months of age, but the enrollment process may take months, learn the requirements of your local school districts and the recommended timeline for beginning the enrollment process.) 	<ul style="list-style-type: none"> - Approximately 12% of VBLW children with normal intelligence have a language disability: <ul style="list-style-type: none"> • Decreased language comprehension • Decreased expressive language skills vocabulary & word finding • Articulation & fluency disorders
Cognitive	<ul style="list-style-type: none"> - Assess early verbal and nonverbal cognitive skills between 30 and 48 months of age with standardized assessment test 	<ul style="list-style-type: none"> - Refer to multidisciplinary neurodevelopmental assessment if atypical development is suspected - Consider referral to pediatric psychologist if development appears delayed or atypical - For therapeutic intervention in any of the above areas of development: <ul style="list-style-type: none"> • 12-36 months of age - same as above • 33-60 months of age -same as above 	<ul style="list-style-type: none"> - May see difficulties with memory, attentive, perceptual motor skills, non-verbal reasoning & problem solving - Mental retardation occurs in 4-5% of LBW infants
Social Adaptive	<ul style="list-style-type: none"> - Subjective assessment at each visit - Standardized assessment at 36-48 months 	<ul style="list-style-type: none"> - Encourage age/developmental level appropriate skills - Facilitate opportunities for appropriate peer interaction 	<ul style="list-style-type: none"> - Review developmentally appropriate behavioral expectations - Increased risk for conduct disorder, hyperactivity & inattention - Some children exhibit shyness, unassertiveness & withdrawn behavior
School Performance	<ul style="list-style-type: none"> - Review any daycare or preschool experiences & performance - Monitor attention skills 	<ul style="list-style-type: none"> - B-3 or 3-5 year programming as indicated - Consider assessment of motor skill prior to school entry 	<ul style="list-style-type: none"> - Review birthdate vs due date as an important consideration relative to Kindergarten entry - Visual motor & fine motor difficulties are more common in LBW children and can adversely impact early school performance
Family Support	<ul style="list-style-type: none"> - Assess parenting skills and understanding of appropriate child development and behavior for their child. If prescribing therapeutic programs, when necessary, assist parents in follow through with assessment and enrollment processes for any referrals. Parents at highest risk for difficulty following through are adolescent parents, those with less than high school education, those in extreme poverty, and any parent with multiple stressors. - Establish goals with the family's input, support siblings & other family members 	<ul style="list-style-type: none"> - Consider referral to Family Resources Coordinator (available in most early intervention programs and through the public health department) to help parents understand and access evaluations and services for their child - Provide requested medical and developmental reports to support parent's application to the intervention program and to social and financial support agencies - Refer to literature resources and organizations for specific disorders (e.g. ARC, POP...) - Refer to community resources, respite care, parent support groups, etc. 	

II Critical Elements of Care by Age of Child

Age 5-13 Years - Late Childhood

AREA OF FOCUS	ASSESSMENT	INTERVENTIONS REFERRAL RESOURCES	ANTICIPATORY GUIDANCE
Medical Evaluation Interim History	<ul style="list-style-type: none"> - General Health - Hospitalizations 		<ul style="list-style-type: none"> - Reiterate that most LBW NICU graduates do not develop adverse outcomes for which they are at higher risk. (Avoid "vulnerable child" syndrome)
Growth	<ul style="list-style-type: none"> - Assess height and weight at each visit - Plot on standard growth grids 		<ul style="list-style-type: none"> - Some children show continued catch up growth in the early school years
Nutrition/Feeding	<ul style="list-style-type: none"> - Assess nutrition and feeding 	<ul style="list-style-type: none"> - Nutritionist referral as indicated 	
Vision	<ul style="list-style-type: none"> - Vision screening examination at 4-6 years and 9-12 years of age 	<ul style="list-style-type: none"> - Referral to ophthalmologist or optometrist if history or screening exam suggest visual problems 	
Hearing	<ul style="list-style-type: none"> - Hearing screening examination at 4-6 years of age; 	<ul style="list-style-type: none"> - Refer to audiologist if problems suspected. 	
Special Health Concerns	<ul style="list-style-type: none"> - Assess for special health concerns in the LBW population: <ul style="list-style-type: none"> • RAD/pulmonary function • Seizure disorder • Infections, otitis • Residual scars • Other 	<ul style="list-style-type: none"> - Consultation with subspecialists as indicated 	<ul style="list-style-type: none"> - For children with ongoing pulmonary disease: <ul style="list-style-type: none"> • Exercise tolerance • Persistence of pulmonary function abnormalities - Generally health issues have resolved or greatly attenuated by school age - Some school age former premies become very self conscious about scars. The appearance of some scars may be significantly improved by plastic surgery but no revision should be done until the child can fully understand and consent to the procedure.

II Critical Elements of Care by Age of Child

Age 5-13 Years - Late Childhood

AREA OF FOCUS	ASSESSMENT	INTERVENTIONS REFERRAL RESOURCES	ANTICIPATORY GUIDANCE
DEVELOPMENTAL BEHAVIORAL ASSESSMENT	<ul style="list-style-type: none"> - Monitor for overactivity, temper tantrums, perseveration (tends to improve as approach adolescence) and for symptoms of distractibility, irritability, unhappiness, low frustration tolerance, fears, disobedience, poor motivation and sleep difficulties (tend to persist or increase in LBW children as move into adolescence) 	<ul style="list-style-type: none"> - Parenting and behavioral counseling and intervention as indicated 	<ul style="list-style-type: none"> - Monitor for overactivity, irritability, or impulsiveness
Temperament/ Rhythmicity			
Sensory/ Motor	<ul style="list-style-type: none"> - Monitor for minor motor concerns: (in office or refer) <ul style="list-style-type: none"> • Incoordination, clumsiness • Poor fine motor skills • Balance difficulties 	<ul style="list-style-type: none"> - Interface as necessary with teacher/school system - Referral Resources: <ul style="list-style-type: none"> • OT/PT • Neurodevelopmental specialist 	<ul style="list-style-type: none"> - Increased incidence of clumsiness, fine motor difficulties, etc. (although many children do not have problems) - Encourage community based activities, such as recreational sports programs, "Little Gym", etc. as well as playground time
Language	<ul style="list-style-type: none"> - Monitor articulation, expressive and receptive language and language processing skills 	<ul style="list-style-type: none"> - Refer for communication assessment as indicated 	<ul style="list-style-type: none"> - At risk for impaired verbal ability and auditory memory skills
Cognitive	<ul style="list-style-type: none"> - Monitor for overall cognitive skills as well as for possible specific learning disabilities 	<ul style="list-style-type: none"> - Refer to public school district or psychologist if delays in cognition or learning disability suspected 	<ul style="list-style-type: none"> - Children less than or equal to 2000 gm BW have higher rate of mild neurologic abnormalities and lower receptive vocabulary, reading and mathematics scores than heavier LBW children - Specific deficits in visual spatial skills
Social Adaptive	<ul style="list-style-type: none"> - Monitor social-emotional development 	<ul style="list-style-type: none"> - Refer parents to the public school district for evaluations if delays in cognitive, communication, or social skills are suspected - Refer to school or community counseling services, mental health services, YMCA and other community recreation programs, etc. as indicated 	<ul style="list-style-type: none"> - Shyness; lower peer approach and interaction skills may be seen - 7-10% LBW children have higher than average rate of behavioral difficulties both anxious and depressive
School Performance	<ul style="list-style-type: none"> - Assess school readiness skills between 4 and 6 years old - Monitor for signs of hyperactivity, impulsivity and inattention - Monitor academic performance, particularly in 1st and 4th grades (visual-motor perceptual skills evidenced in difficulties with reading, writing and math) and at the beginning of middle school (multiple class schedule and expectations for increased abstract thinking). 	<ul style="list-style-type: none"> - Assess with teachers, parents, school nurse. Consider behavioral, medical and educational interventions. Refer as necessary to neurologist, psychologist, ADHD assessment clinics, etc. - Provide any medical documentation that is necessary for obtaining increased educational services, as needed 	<ul style="list-style-type: none"> - ADHD is associated with learning disability (25-35%) - Increased academic demands @ 8-9 yrs. - abstract thinking skills, increased pencil/paper work - @ 8 yrs. - 15 to 20% of LBW children are classified as needing special education services <ul style="list-style-type: none"> • This increases to 50% in <1000 gm birth weight
Family Support	<ul style="list-style-type: none"> - Assess parenting skills and understanding of appropriate child development and behavior for their child. If prescribing therapeutic programs, when necessary assist parents in follow through with assessment and enrollment processes for any referrals. Parents at highest risk for difficulty following through are adolescent parents, those with less than high school education, those in extreme poverty, and any parent with multiple stressors. - Establish goals with the family's input, support siblings & other family members 	<ul style="list-style-type: none"> - Provide requested medical and developmental reports to support parent's application to the intervention program and to social and financial support agencies - Refer to literature resources and organizations for specific disorders (e.g. ARC, POP...) - Refer to community resources, respite care, parent support groups, etc. 	

II Critical Elements of Care by Age of Child

13 to 21 Years – Adolescence

AREA OF FOCUS	ASSESSMENT	INTERVENTIONS REFERRAL RESOURCES	ANTICIPATORY GUIDANCE
MEDICAL EVALUATION			
Interim History <i>AAP Recommended Visits: Annual</i>	<ul style="list-style-type: none"> - Obtain interim history including health and psycho-emotional concerns, academic performance, sexuality and risk-taking behaviors - Discuss with adolescent continuing concerns he/she might have relating to prematurity or health/developmental problems 		<ul style="list-style-type: none"> - Start preparing adolescent to enter adult health care system - Encourage adolescent to assume personal responsibility for own health care commensurate with age and allow to participate in health care decisions
Growth	<ul style="list-style-type: none"> - Assess height and weight at each visit. Plot on standardized growth grid 		
Nutrition/ Feeding	<ul style="list-style-type: none"> - Assess nutrition 	<ul style="list-style-type: none"> - Referral to Nutritionist as needed 	
Vision	<ul style="list-style-type: none"> - Perform visual acuity screen at 15 years and 18 years of age or if concerns arise 	<ul style="list-style-type: none"> - Referral to Ophthalmologist or Optometrist as indicated 	
Hearing	<ul style="list-style-type: none"> - Perform hearing screen at 15 years and 18 years or for interim concerns 	<ul style="list-style-type: none"> - Refer to Audiologist as indicated 	
Special Health Concerns	<ul style="list-style-type: none"> - Assess for continued health concerns related to prematurity, if any: <ul style="list-style-type: none"> •RAD/pulmonary function •Residual scars •Other 	<ul style="list-style-type: none"> - Consultation with subspecialists as indicated - Plastic surgery consultation upon child's request for scar revisions 	<ul style="list-style-type: none"> - Exercise tolerance - Persistence of pulmonary function abnormalities - Some school age former preemies become very self conscious about scars - The appearance of some scars may be significantly improved by plastic surgery but no revision should be done until the child can fully understand and consent to the procedure

II Critical Elements of Care by Age of Child

13 to 21 Years – Adolescence

AREA OF FOCUS	ASSESSMENT	INTERVENTIONS REFERRAL RESOURCES	ANTICIPATORY GUIDANCE
DEVELOPMENTAL BEHAVIORAL ASSESSMENT			
Temperament/ Rhythmicity			
Sensory/Motor	<ul style="list-style-type: none"> - Continue to monitor for minor motor concerns 		<ul style="list-style-type: none"> - Continue to encourage recreational sports activities and fitness programs
Language	<ul style="list-style-type: none"> - Continue to monitor for articulation, expressive and receptive language and language processing skills 	<ul style="list-style-type: none"> - Continue interventions as indicated 	
Cognitive	<ul style="list-style-type: none"> - Monitor for overall cognitive skills as well as for possible specific learning disabilities 	<ul style="list-style-type: none"> - Refer for psychological assessment as needed 	<ul style="list-style-type: none"> - May need to interface frequently with teacher both for students qualifying for services, but especially for students that do not meet school criteria for assistance (a not insignificant group)
Social Adaptive	<ul style="list-style-type: none"> - Monitor for signs of low self-esteem, depression, anxiety, peer relationships/difficulties or other problems with social competency 	<ul style="list-style-type: none"> - Referral to appropriate mental health services as indicated 	<ul style="list-style-type: none"> - Continue facilitation of social activities <ul style="list-style-type: none"> • Peer interaction • School activities • Community clubs and teams, church or other resources.
School Performance	<ul style="list-style-type: none"> - Monitor academic performance particularly at the transition from middle school to high school. - Monitor for signs of inattention or distractibility - If concerns, in addition to physiologic causes, consider substance abuse and family stress 	<ul style="list-style-type: none"> - Referral for academic or vocational guidance counseling as indicated - Refer to ADHD clinic or other mental health specialist as indicated 	<ul style="list-style-type: none"> - Support systems such as tutoring, special school based homework assistance etc. may be needed due to continued effect of minor LD/ADHD and neurodevelopmental sequelae. - Review potential need for special untimed SAT/ACT or other college entry tests for children with ADHD/LD
Family Support	<ul style="list-style-type: none"> - Assess parenting skills and understanding of appropriate child development and behavior for their child. If prescribing therapeutic programs, when necessary assist parents in follow through with assessment and enrollment processes for any referrals. Parents at highest risk for difficulty following through are adolescent parents, those with less than high school education, those in extreme poverty, and any parent with multiple stressors. - Establish goals with the family's input, support siblings & other family members 	<ul style="list-style-type: none"> - Provide requested medical and developmental reports to support parent's application to the intervention program and to social and financial support agencies - Refer to literature resources and organizations for specific disorders (e.g. ARC, POP...) - Refer to community resources, respite care, parent support groups, etc. 	

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 in accordance 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 children 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

Gestational Age at Birth, wk	Age at Initial Examination, 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 through 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 occurrence, 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 multifaceted 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 ability to use cultural resources in interventions
- an acknowledgement of the integrity and value of all cultures¹³

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.

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Section V. Appendices

1. A prenatal visit is recommended for parents who are at high risk, for first-time parents, and for those who request a conference. The prenatal visit should include anticipatory guidance, pertinent medical history, and a discussion of benefits of breastfeeding and planned method of feeding per AAP statement "The Prenatal Visit" (1996).
2. Every infant should have a newborn evaluation after birth. Breastfeeding should be encouraged and instruction and support offered. Every breastfeeding infant should have an evaluation 48-72 hours after discharge from the hospital to include weight, formal breastfeeding evaluation, encouragement, and instruction as recommended in the AAP statement "Breastfeeding and the Use of Human Milk" (1997).
3. For newborns discharged in less than 48 hours after delivery per AAP statement "Hospital Stay for Healthy Term Newborns" (1995).
4. Developmental, psychosocial, and chronic disease issues for children and adolescents may require frequent counseling and treatment visits separate from preventive care visits.
5. If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.
6. If the patient is uncooperative, rescreen within 6 months.
7. All newborns should be screened per the AAP Task Force on Newborn and Infant Hearing statement, "Newborn and Infant Hearing Loss: Detection and Intervention" (1999).
8. By history and appropriate physical examination: if suspicious, by specific objective developmental testing. Parenting skills should be fostered at every visit.
9. At each visit, a complete physical examination is essential, with infant totally unclothed, older child undressed and suitably draped.
10. These may be modified, depending upon entry point into schedule and individual need.
11. Metabolic screening (eg, thyroid, hemoglobinopathies, PKU, galactosemia) should be done according to state law.
12. Schedule(s) per the Committee on Infectious Diseases, published annually in the January edition of *Pediatrics*. Every visit should be an opportunity to update and complete a child's immunizations.
13. See AAP *Pediatric Nutrition Handbook* (1998) for a discussion of universal and selective screening options. Consider earlier screening for high-risk infants (eg, premature infants and low birth weight infants). See also "Recommendations to Prevent and Control Iron Deficiency in the United States". *MMWR*. 1998;47 (RR-3):1-29.
14. All menstruating adolescents should be screened annually.
15. Conduct dipstick urinalysis for leukocytes annually for sexually active male and female adolescents.
16. For children at risk of lead exposure consult the AAP statement "Screening for Elevated Blood Levels" (1998). Additionally, screening should be done in accordance with state law where applicable.
17. TB testing per recommendations of the Committee on Infectious Diseases, published in the current edition of *Red Book: Report of the Committee on Infectious Diseases*. Testing should be done upon recognition of high-risk factors.
18. Cholesterol screening for high-risk patients per AAP statement "Cholesterol in Childhood" (1998). If family history cannot be ascertained and other risk factors are present, screening should be at the discretion of the physician.
19. All sexually active patients should be screened for sexually transmitted diseases (STDs).
20. All sexually active females should have a pelvic examination. A pelvic examination and routine pap smear should be offered as part of preventive health maintenance between the ages of 18 and 21 years.
21. Age-appropriate discussion and counseling should be an integral part of each visit for care per the AAP *Guidelines for Health Supervision III* (1998).
22. From birth to age 12, refer to the AAP injury prevention program (TIPP®) as described in *A Guide to Safety Counseling in Office Practice* (1994).
23. Violence prevention and management for all patients per AAP Statement "The Role of the Pediatrician in Youth Violence Prevention in Clinical Practice and at the Community Level" (1999).
24. Parents and caregivers should be advised to place healthy infants on their backs when putting them to sleep. Side positioning is a reasonable alternative but carries a slightly higher risk of SIDS. Consult the AAP statement "Changing Concepts of Sudden Infant Death Syndrome: Implications for Infant Sleeping Environment and Sleep Position" (2000).
25. Age-appropriate nutrition counseling should be an integral part of each visit per the AAP *Handbook of Nutrition* (1998).
26. Earlier initial dental examinations may be appropriate for some children. Subsequent examinations as prescribed by dentist.

● = to be performed	★ = to be performed for patients at risk
S = subjective, by history	○ = objective, by a standard testing method
← → = the range during which a service may be provided, with the dot indicating the preferred age.	

American Academy of Pediatrics



NB: Special chemical, immunologic, and endocrine testing is usually carried out upon specific indications. Testing other than newborn (eg, inborn errors of metabolism, sickle disease, etc) is discretionary with the physician.

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Appendix 2

GUIDELINES FOR NURSERY DISCHARGE INFORMATION

1. Significant **perinatal history** -- to include maternal history, prenatal course, medications, drug exposures, social history
2. **Labor and delivery history**, including birth weight, gestational age, appropriateness for gestational age, Apgars, and resuscitation efforts
3. Summary of **hospital course**, including:
 - Nutrition history and present feeding regimen
 - Respiratory course including ventilator support, oxygen needs, apnea and bradycardia, bronchopulmonary dysplasia
 - Neurologic complications, including intraventricular hemorrhage or periventricular leukomalacia, seizures, hydrocephalus
 - Cardiovascular needs
 - Transfusions
 - Infections
 - Surgical procedures, central lines used, exchange transfusions, etc.
 - Ophthalmology evaluations
 - Any other major complications, such as GE reflux, necrotizing enterocolitis, etc.
4. Pertinent **laboratory studies**:
Highest bilirubin, most recent hemoglobin and reticulocyte count, newborn metabolic screening, etc.
5. Pertinent **radiologic and other studies**: Cranial ultrasound, echocardiogram, pneumogram etc.
6. **Discharge medications** and levels
7. **Immunizations**
8. **Hearing evaluation**
9. **Discharge physical**, including weight, length, and head circumference
10. **Home equipment needs**
11. **Home nursing and therapy needs** (occupational, physical, or speech therapy)
12. **Follow-up appointments** with all services involved

Adapted from Bernbaum J, Hoffman-Williamson M: Primary Care of the Preterm Infant. St Louis, Mosby Yearbook, 1991

Appendix 3

Indicators Associated with Sensorineural and/or Conductive Hearing Loss:

- A. For use with neonates (birth through age 28 days) when universal screening is not available.**
1. Family history of hereditary childhood sensorineural hearing loss.
 2. In utero infections, such as cytomegalovirus, rubella, syphilis, herpes, and toxoplasmosis.
 3. Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal.
 4. Birth weight less than 1500 grams (3.3 lbs).
 5. Hyperbilirubinemia at a serum level requiring exchange transfusion.
 6. Ototoxic medications, including but not limited to the aminoglycosides, used in multiple courses or in combination with loop diuretics.
 7. Bacterial meningitis.
 8. Apgar scores of 0-4 at one minute or 0-6 at five minutes.
 9. Mechanical ventilation lasting five days or longer.
 10. Stigmata or other findings associated with a syndrome known to include a sensorineural and/or conductive hearing loss.
- B. For use with infants (age 29 days through 2 years) when certain health conditions develop that require rescreening.**
1. Parent/caregiver concern regarding hearing, speech, language, and/or developmental delay.
 2. Bacterial meningitis and other infections associated with sensorineural hearing loss.
 3. Head trauma associated with loss of consciousness or skull fracture.
 4. Stigmata or other findings associated with a syndrome known to include a sensorineural and/or conductive hearing loss.
 5. Ototoxic medications, including but not limited to chemotherapeutic agents or aminoglycosides, used in multiple courses or in combination with loop diuretics.
 6. Recurrent or persistent otitis media with effusion for at least three months.
- C. For use with infants (age 29 days through three years) who require periodic monitoring of hearing. Some newborns and infants may pass initial hearing screening but require periodic monitoring of hearing to detect delayed-onset sensorineural and/or conductive hearing loss. Infants with these indicators require hearing evaluation at least every six months until age three years, and at appropriate intervals thereafter.**

Indicators associated with delayed-onset sensorineural hearing loss include:

1. Family history of hereditary childhood hearing loss.
2. In utero infection, such as cytomegalovirus, rubella, syphilis, herpes, or toxoplasmosis.
3. Neurofibromatosis Type II and neurodegenerative disorders.

Indicators associated with conductive hearing loss include:

1. Recurrent or persistent otitis media with effusion.
2. Anatomic deformities and other disorders that affect eustachian tube function.
3. Neurodegenerative disorders.

Position Statement 2000 -Joint Committee on Infant Hearing, American Academy of Pediatrics.

Appendix 4

NEONATAL RISK FACTORS FOR ADVERSE NEURODEVELOPMENTAL OUTCOME

Biologic Factors

Prenatal Factors

- Maternal PKU or HIV
- Prenatal teratogen exposure (e.g. Dilantin or Valproate)
- Prenatal alcohol or substance abuse
- Major congenital anomalies
- Multiple minor physical anomalies
- Small for gestational age
- Maternal tobacco use
- Lack of prenatal care - risk of prematurity and subsequent developmental disabilities is 3-5 times greater in children born to women who do not receive prenatal care
- Family history of deafness

Perinatal and Postnatal Factors

- Birth weight 2500 grams or less, especially if less than 1500 grams birth weight
- Respiratory distress requiring mechanical ventilation
- Asphyxia - Apgar score of four or less at 5 minutes
- Neonatal seizures
- Intracranial hemorrhage or periventricular leukomalacia
- Hyperbilirubinemia - levels exceeding need for exchange transfusion
- Microcephaly or macrocephaly (more than 2SD above or below mean)
- Central nervous system infection
- Congenital infection (TORCH)
- Abnormal neonatal neurologic exam
- Failure to thrive

Environmental Factors

- Maternal age less than 16 years
- Parental mental retardation
- Parental psychiatric disorder
- Parental alcohol or substance abuse
- Lack of permanent housing
- Inadequate care giving
- History of abuse or neglect in parent or sibling
- Extreme poverty

Appendix 5 NEURODEVELOPMENTAL SCREENING AND TESTS

Definitions:

Developmental Screening - a brief formal evaluation of developmental skills intended to identify those children with suspect problems who should receive further assessment

Developmental Surveillance - a more informal approach to the detection of developmental problems than developmental screening in which the primary care provider should identify parental concerns and make regular skilled observations of a child's behavior to monitor his/her developmental progress. It is suggested that this ideally will include a two level screening system (basic and focused), a combination of formal screening tools with informal observations, repeated measures at different ages, and the use of multiple sources of information, especially parental report.

Developmental Monitoring Program for High-Risk Infants and Preschoolers:

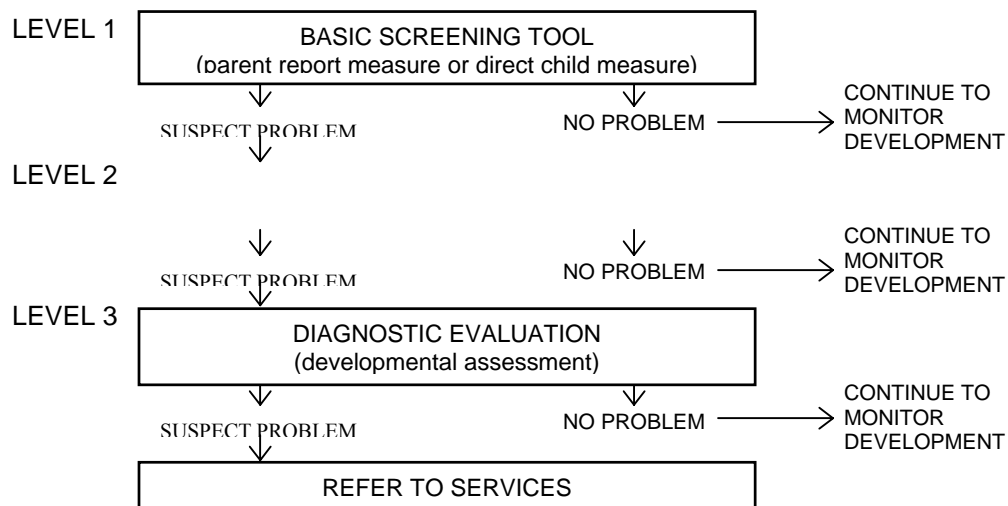
- Goals:**
- Identification of pre-school age children with developmental delay or mental retardation, cerebral palsy, language disorders, and/or autism
 - Identification of hearing or vision impairments
 - Monitoring for signs of potential ADHD and/or learning disabilities
(Identifying children with specific learning disabilities prior to the development of academic failure is difficult.)
 - Provide access to early intervention services where indicated

A Protocol for Developmental Monitoring of High-Risk Infants and Children

In addition to informal observations and review of parent concerns at each well child visit:

- Determine the presence of biologic and environmental risk factors
- Screen the development of children at 4, 8, 12, 18, 24, 36 and 48 months corrected age and when a parent/guardian expresses a specific concern.
- Use a professionally administered general developmental screening test and a neuromotor screen at 4 months
- Use a parent report measure as the first level screen for all infants and children after the 4 month visit
- Use a language screen for children 18 months to 3 years of age with language delay on first or second level screen and when a parent/guardian expresses a concern about language delay.

A MODEL DEVELOPMENTAL MONITORING PROGRAM



The following is a selection of tests. None are ideal. The list has many of the most commonly used tests.

** indicates recommended tests*

Developmental Screening Tests: Level 1 - Basic Multidomain Screening

Goal: Identify all or nearly all children with the problem with few false positives (normal children misclassified as abnormal) and little use of professional time. Need a comprehensive but brief screening tool. Children who are suspect or abnormal on the first level screen should have the results confirmed by testing with a second level screen or targeted screen or they should be referred for further evaluation.

Tools:

- *Ages and Stages Questionnaire (Bricker)
- *Child Development Inventories
 - (formerly - Minnesota Infant Developmental Inventory
 - Minnesota Child Development Inventory
 - Minnesota Preschool Development Inventory)
- Revised Parent Developmental Questionnaires (based on Gesell)
- Revised Denver Prescreening Developmental Questionnaire - Revised (PDQ-R)
- First STEp (Screening Test for Evaluating Preschoolers)
- *Denver II
 - Bayley Infant Neurodevelopmental Screener (BINS)
 - Developmental Profile II (1986)
 - Brigance Screens

Developmental Screening Tests: Level 2 - Focused Screening

Second level screens are administered by the physician, nurse, nurse-practitioner, or other primary care provider. Direct observation and examination of the child complements the results from the first level screen. These tests should be brief - 15-20 minutes to complete, but cover all appropriate developmental domains.

These tools are to confirm suspect findings from the first level screen and are used to assess children and families for whom first level screen is inappropriate. They will clarify the need for referral for early intervention services and/or other evaluation. Many health care professionals prefer to refer all children rated suspect on the first level screen rather than conduct a second-level screen.

Multidomain

- Denver II
- *Early Screening Inventory
 - Early Screening Profile (ESP)
 - Clinical Adaptive Test/Clinical Linguistic Auditory Milestone Test(CAT/CLAMS)
- *The Revised Developmental Screening Inventory (Knobloch)
 - Vineland Adaptive Behavior Scales
- *Developmental Indicators for the Assessment of Learning -Revised (DIAL-R)
- *Batelle Developmental Inventory Screening Test (BDIST)
- *Miller Assessment for Preschoolers
 - Preschool Screening System
 - First STEp
- *Bayley Infant Neurodevelopmental Screener (BINS)

Targeted screens - Language and Neuromotor Screens

Targeted screens may be used primarily by health professionals with a special interest in developmental disabilities.

Language:

- *MacArthur Communication Development Inventories
- *Early Language Milestone Scale
- Receptive-Expressive Emergent Language Scale (REEL)
- Clinical Linguistic and Auditory Milestone Scale (CLAMS)
- *Language Development Survey

Motor:

- *Infant Motor Screen
- *Chandler Movement Assessment of Infants Screening (in progress)
- Bayley Infant Neuromotor Screener (BINS)
- *Milani Comparetti Motor Development Screening Test
- *Alberta Infant Motor Scale (AIMS)
- Primitive Reflex Profile
- Harris Infant Neuromotor Test (HINT)

Developmental Tests: Level 3

These are more in-depth tests generally performed by professionals in the subspecialty area. Most tests require training in their administration.

Multiple Domains Assessed:

- Miller Assessment for Preschoolers
- Batelle Developmental Inventory
- McCarthy Scales of Children's Abilities
- Bayley Scales of Infant Development
- Stanford-Binet Intelligence Scale

Language Assessment

- McArthur Communicative Development Inventories
- Infant-Toddler Language Scale (Louis Rossetti)
- Peabody Picture Vocabulary Test - Revised (PPVT-R)
- Receptive-Expressive Emergent Language Scale (REEL)
- Preschool Language Scale - 3
- Sequenced Inventory of Communication Development - Revised

Motor Assessment

- Alberta Infant Motor Scale (AIMS)
- Movement Assessment of Infants (MAI)
- Peabody Developmental Motor Scales

Hearing

- Otoacoustic Emissions
- Auditory Brainstem Response
- Visual Reinforcement Audiometry (over 6 months developmental skill level)

Appendix 6

RECOMMENDATIONS FOR CAR SEAT POSITIONING

Car Seats and Car Beds:

Positioning LBW infants properly in a car seat can be difficult, particularly if the infant is still small at the time of hospital discharge. Most safety restraints currently on the market are designed for infants weighing 3.5 kilograms (7 pounds). Three manufacturers, Baby Trend, Safetyfirst/Costco and Evenflo, make a car seat model that is smaller. It is advised to select a car seat with: 1) a crotch strap distance of less than 5.5 inches from the seat back, and 2) a distance of less than 8 inches from the lowest shoulder strap position to the seat bottom.

A significant concern for car seat positioning of the LBW infant is respiratory compromise. Premature and LBW infants are at greater risk for poor oxygenation in the semi-upright position in a car seat. AAP recommends that all infants born before 37 weeks gestation have a car seat check, including assessment for possible oxygen desaturation, before hospital discharge. Although infants must pass a car seat test prior to discharge, it is still recommended that the infant be closely monitored during travel, and if possible have an adult ride next to the infant in the back seat. For infants at risk of respiratory compromise, travel should be kept to a minimum.

Car Seat Position: All infants, including preterm infants, must ride in a rear-facing car seat until 12 months of age (corrected age for preemies) AND at least 20 pounds. If the vehicle seat slopes such that the infant's head flops forward, the car seat should be installed at a 45 degree angle (reclined halfway back). If needed, a roll of cloth or newspaper can be wedged under the foot end of the car seat to achieve this angle.

Infant Positioning: The infant's buttocks should be against the back of the car seat. It is not permitted and is unsafe to pad a car seat behind the infant's back or under the buttocks. If there is additional space between the infant and the crotch strap (when buttocks are fully back), this space should be filled in to assure a snug fit and prevent slouching. A rolled blanket can be used for padding between the infant's crotch and the buckle. Blanket rolls can also be placed on either side of the infant for lateral support of the head and neck.

The position of the shoulder slot used for the shoulder strap must be at or below the level of the infant's shoulders. The harness should fit snugly and the chest clip positioned at the level of the axilla. A car seat with a tray or shield will initially be too big for LBW infants.

Parents should avoid using bulky snowsuits or wrapping the infant in blankets. An extra blanket can be placed OVER the infant once positioned properly in the car seat.

See www.aap.org/policy/01351.html (*Safe Transportation of Premature and Low Birth Weight Infants*) for illustrations of the various positioning recommendations described above.

Car Beds: Infants with documented desaturation, apnea, or bradycardia in a semiupright position should travel in a supine or prone position in an alternative safety device. While not crash-tested, car beds offer an alternative for infants with exceptional needs. Car beds are not as safe as car seats. Use of a car bed should be minimized and used only for absolutely necessary trips. Before transitioning from a car bed to a car seat, an oximetry test while positioned in the infant's personal car seat is needed.

Appendix 7

LOCAL AND COMMUNITY RESOURCES – WASHINGTON STATE

CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) COORDINATORS

<http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>

AND

LEAD FAMILY RESOURCES COORDINATORS (FRC)

BY COUNTY

<http://www1.dshs.wa.gov/iteip/countyorglinks.html>

COUNTY	CSHCN	LEAD FRC
<i>Adams</i>	(509)659-3317	(509)488-4074
<i>Asotin</i>	(509)758-3344/3345	(509)758-3181
<i>Benton-Franklin</i>	(509)586-0207 ext. 236	(509)946-5157, ext. 126
<i>Chelan-Douglas</i>	(509)886-6423	(509)664-3781
<i>Clallam</i>	(360)417-2413	(360)374-9340
<i>Clark</i> <i>(SW Washington)</i>	(360)397-8215 ext.3136	(360)896-9912, ext.170
<i>Columbia</i>	(509)382-2181	(509)382-2181
<i>Cowlitz</i>	(360)414-5599	(360)577-2714
<i>Ferry</i> <i>(NE Tri-County Health District)</i>	(509)775-3111	(509)684-5048
<i>Garfield</i>	(509) 843-3412	(509) 843-3412
<i>Grant</i>	(509)766-7960	(509)765-5809
<i>Grays Harbor</i>	(360) 532-8631	(360)533-9414

COUNTY	CSHCN	LEAD FRC
<i>Island</i>	(360)679-7351	(360)679-1039
<i>Jefferson</i>	(360)385-9442	(360)374-9340
<i>King</i>	(206)296-7412	1(800)756-5437 (206) 284-0331
<i>Kitsap</i>	(360) 337-4823	1(800)449-1660 (360)373-2536
<i>Kittitas</i>	(509)962-7023	(509)933-7042
<i>Klickitat</i>	1-888-291-3521 Goldendale 1-888-267-1199 White Salmon	(509)493-1392
<i>Lewis</i>	(360)740-1257	(360)748-4359
<i>Lincoln</i>	(509)725-9213, ext. 31	(509)725-9213, ext.30
<i>Mason</i>	(360)427-9670 ext. 408	(360)426-5430
<i>Okanogan</i>	(509)422-7159 1-800-222-6410	(509) 826-8945
<i>Pacific</i>	(360) 875-9343	(360)642-8586

Section V. Appendices

COUNTY	CSHCN	LEAD FRC
<i>Pend Oreille</i> <i>(NE Tri-County Health District)</i>	(509) 447-3131	(509)684-5048 (Spokane Tribe Lead) (509)258-7502
<i>Pierce</i>	(253)798-6517	(253)798-3775
<i>San Juan</i>	(360)378-4474	(360)378-4474
<i>Skagit</i>	(360)336-9383	(360)416-7570
<i>Skamania</i>	(360)397-8215,ext.3136	(509)493-2662
<i>Snohomish</i>	(425)339-8649	(425)339-4857
<i>Spokane</i>	(509)324-1697	(509)324-1471 Spokane Tribe (509)258-7502
<i>Stevens</i> <i>(NE Tri-County Health District)</i>	(509)684-5048	(509)684-5048
<i>Thurston</i>	(360)754-3351	(360)352-1126
<i>Wahkiakum</i>	(360)795-6207	(360)577-2714
<i>Walla Walla</i>	(509)527-3290	(509)527-3278
<i>Whatcom</i>	(360)738-2522	(360)738-2508, ext. 32093
<i>Whitman</i>	(509)332-6752	(509)332-4420 (509)332-3838
<i>Yakima</i>	(509)574-3260	(509)574-3269

NEURODEVELOPMENTAL CENTERS

http://www.doh.wa.gov/cfh/mch/documents/neurodevelopmental_centers.doc

Fourteen Neurodevelopmental Centers are supported, in part, by Washington's Dept. of Health -- CSHCN Program funding to provide evaluation, diagnosis, coordinated treatment planning, and specialized therapy to children with a variety of developmental or neurodevelopmental conditions.

Boyer Children's Clinic 1850 Boyer Avenue East Seattle, Washington 98112	(206) 325-8477 FAX (206) 323-1385 Website: www.boyercc.org
Chelan-Douglas Developmental Services 1305 Kittitas Wenatchee, Washington 98801	(509) 662-2000 FAX (509) 662-4562
Children's Therapy Center 10811 Kent-Kangley Road Kent, Washington 98031-7108	(253) 854-5660 FAX (253) 854-7025 Website: ctckids.org
Children's Village 3801 Kern Road Yakima, Washington 98902	(509) 574-3260 FAX (509) 574-3210
Good Samaritan Hospital Children's Therapy Unit 407 15th Avenue SE, Suite 100 Puyallup, Washington 98372	(253) 697-5220 FAX (253) 697-5145 Website: www.goodsamhealth.org
Holly Ridge Center, Inc. 5112 Northwest Taylor Road Bremerton, Washington 98312	(360) 373-2536 FAX (360) 373-4934 Website: www.hollyridge.org
Kindering Center 16120 Northeast 8th Street Bellevue, Washington 98008	(425) 747-4004 FAX (425) 747-1069 Website: www.kindering.org
Mary Bridge Children's Health Center Neurodevelopmental Program 311 South "L" Street (MS: 311-3 NDP) Post Office Box 5299 Tacoma, Washington 98415-0299	(253) 403-1449 FAX (253) 403-8674 Website: www.MultiCare.org
Progress Center 1600 Third Ave Longview, Washington 98632	(360) 425-9810 FAX (360) 425-1053 Website: www.theprogresscenter.org
Providence Everett Medical Center Providence Children's Center 900 Pacific Avenue -- 1 th Floor Post Office Box 10670 Everett, Washington 98206-1067	(425) 258-7069 FAX (425) 258-7618 Website: www.providence.org
Skagit Preschool and Resource Center (SPARC) 320 Pacific Place Mount Vernon, Washington 98273	(360) 416-7570 FAX (360) 416-7580
Spokane Guild's School and Neuromuscular Center 2118 W Garland Avenue Spokane, Washington 99205	(509) 326-1651 FAX (509) 326-1658 Website: www.guildschool.org

NEURODEVELOPMENTAL CENTERS

St. Joseph Hospital (360) 715-6430
Children's Neurodevelopmental Program FAX (360) 715-6562
809 East Chestnut Street
Bellingham, Washington 98225-5298

Valley Medical Center (425) 656-4215
Children's Therapy Services FAX (425) 656-5075
400 South 43rd Website: www.valleymed.org
Renton, Washington 98055

ASSOCIATED TERTIARY CENTERS*

Center on Human Development and Disability Clinical (206) 685-1255
Training Unit FAX (206) 543-5771
High Risk Infant Follow-up
Box 357920
Seattle, Washington 98195-7920

Children's Hospital and Regional Medical Center (206) 987-2204
Neurodevelopmental Program FAX (206) 987-3824
Post Office Box 5371 (CH-47)
Seattle, Washington 98105

Madigan Army Medical Center (253) 968-2310
Developmental Pediatric Clinic
Tacoma, Washington 98431-5473

*DOH does not contract for services with these associated tertiary centers.

Appendix 8

GLOSSARY OF ABBREVIATIONS

AAP -	American Academy of Pediatrics	LD -	Learning disability
ACT -	a college entrance examination similar to the SAT	NEC -	Necrotizing enterocolitis
ADHD -	Attention deficit hyperactivity disorder	NICU -	Neonatal intensive care unit
AGA -	Appropriate for gestational age	OFC -	Occipital Frontal Circumference; head circumference
ARC -	Association for retarded citizens	OT -	Occupational therapist
B-3 -	Birth to three program	PCP -	Primary Care Provider
BAER -	Brainstem auditory evoked response	PDA -	Patent Ductus Arteriosus
BW -	Birth weight	PHN -	Public health nurse
CA -	Corrected age (for prematurity)	POP -	Parents of prematures (organization)
CEC -	Critical Elements of Care	PT -	Physical therapist
CLD -	Chronic lung disease	RAD -	Reactive airway disease
CP -	Cerebral palsy	RD -	Registered dietician
CPR -	Cardiopulmonary resuscitation	RN -	Registered nurse
CPS -	Children's Protective Services	R/O -	Rule out
CSHCN -	Children with Special Health Care Needs	ROP -	Retinopathy of prematurity
D/C -	Discharge	RSV -	Respiratory syncytial virus
EI -	Early intervention (program)	SAT -	Scholastic aptitude test
ELBW -	Extremely low birth weight; used for infants at or under 1000 grams birth weight	SD -	Standard deviation
ENT -	Ear, nose and throat	SGA -	Small for gestational age
FRC -	Family resources coordinator	SIDS -	Sudden infant death syndrome
FTG -	Failure to grow	SLP -	Speech and language pathologist
GA -	Gestational age	S/P -	Status post
GERD -	Gastroesophageal reflux disease	SW -	Social work
GI -	Gastrointestinal	VLBW -	Very low birth weight; used for infants at or under 1500 grams birth weight
HRI f/u -	High risk infant follow-up program	WIC -	Women, infants and children (program)
Ht -	Height	Wt -	Weight
LBW -	Low birth weight; used for infants at or under 2500 grams birth weight		