



# Watching Your Low Birth Weight Child Grow

TIPS FOR PARENTS

**Created by** Mary Bridge Children's Hospital & Health Center High Risk Infant Follow-Up Program

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**Watching Your Low Birth Weight Child Grow: Tips for Parents** is a booklet for parents of children, age birth to three years, who were born weighing five pounds or less. Creation of this booklet was coordinated by Mary Bridge Children's Hospital High Risk Infant Follow Up Program. It was funded by the Washington State Department of Health, Children with Special Health Care Needs program.

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The recommendations in this booklet are based upon information contained in the document, "Critical Elements of Care of the Low Birth Weight NICU Graduate", a guide written for doctors and nurse practitioners who provide well-baby/child care for low birth weight babies and children. These guidelines were developed by a Washington State consensus-based, multidisciplinary task force.

The document "Critical Elements of Care of the Low Birth Weight NICU Graduate" can be found at: <http://depts.washington.edu/medhome/CEC/CEC.htm>

If you have questions or would like additional copies of the booklet **Watching Your Low Birth Weight Child Grow: Tips for Parents** call: 253-403-5525.

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 outcome for some patients may be obtained from practices other than those recommended in this document. This booklet is not intended to replace sound clinical judgment or individualized consultation with specialists regarding patient care needs.

# Watching Your Low Birth Weight Child Grow

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**As parents, we watch our children carefully** to make sure they are growing and developing. We want to know if they can see, hear, move, learn, and interact with the world around them.

Most children who were born early and small will grow and develop well. However, children who are born early are at risk for problems in their development. This risk increases the smaller and earlier a baby was born. These children need their parents, primary health care providers (doctors and nurse practitioners), teachers, and others to watch their development very closely. When problems are present not everything can be “fixed” but a lot can be done to help.

Your child’s primary health care provider will work with you to watch your child grow and develop. This booklet will give you information about your low birth weight child from birth to three years, including:

- areas of growth and development to follow closely
- schedules for recommended monitoring or testing
- what parents can do to encourage their children’s growth and development
- professionals who can help
- where to go for more information

## ADJUSTED AGE

### **Remember to use “adjusted age” for the first 2 to 3 years of your baby’s life!**

It is important to use your child’s “adjusted age” (also called “**corrected age**”) when comparing his growth and abilities to other children or to growth and developmental charts.

To figure out your baby’s adjusted age, take his actual age (in months) and subtract how many weeks or months he was early.

Example: Your baby is six months old. He was born two months early.  $6 - 2 = 4$ . Your baby’s adjusted age is four months.

In this example, a baby that is six months old but was born 2 months early would be only expected to show the growth and developmental skills of a four-month-old baby.

# Growth, Nutrition, Feeding and Reflux



## What Parents Should Know

### **GROWTH**

- Growing well requires good nutrition. Good nutrition is necessary to build a healthy body and brain.
- Your baby's weight, length and head circumference will be checked at every primary health care visit. These measurements will be compared to earlier ones to make sure she is growing well. It is not important to compare her growth with other children her age. What is important is that she is growing at a steady rate.
- Professionals should consider her adjusted age (for at least the first two to three years of life) when plotting growth on standard growth charts.
- Low birth weight infants often grow differently from infants who were born full term and at typical weights. Some children grow quickly in the first year of life. Others may grow slowly the first years and catch up at age two or three. Some continue to be small beyond three years of age with a gradual catch up by six to eight years of age. Others remain small.

### **NUTRITION**

- Every low birth weight baby needs to have a nutritional plan that promotes growth.
- Babies should stay on breast milk or formula until they are at least one year *adjusted age*. Most babies can then be switched to whole milk.
- Usually, baby foods such as cereals and pureed vegetables and fruits are started at six months *adjusted age*. You should talk with your baby's primary health care provider to make sure your baby is ready for eating baby foods. Your baby may be ready to start baby foods if she has good head control and is interested in your food.

### **FEEDING**

Many parents report that their low birth weight babies have problems with feeding. Feeding problems can occur for a variety of reasons. Low birth weight babies may:

- tire easily with feedings
- become anxious
- refuse to eat or take only a small amount
- choke or gag
- have problems with food textures

### **REFLUX**

- Reflux (also called gastroesophageal reflux or GER) is more common in low birth weight infants than in full term, typical weight infants. (*continued next page*)

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- Reflux occurs when stomach contents and acid flow up into the esophagus (the swallowing tube connecting mouth and stomach).
- Severe reflux may interfere with feeding and with growing.
- Sometimes positioning changes are recommended or medication is prescribed.



## **What Parents Can Do**

### **GROWTH**

- Make sure that your baby is weighed and measured for length and head circumference at well-baby visits and more often if there are any concerns.
- Talk with your baby's primary health care provider if you have any concerns about how well she is growing.

### **NUTRITION**

- Make a nutrition plan with your baby's primary health care provider or registered dietitian.
- Update your baby's nutrition plan frequently.
- If your baby or child is not gaining weight and growing as expected, talk to your baby's primary health care provider about your concerns. You may be referred to a pediatric registered dietitian. A pediatric registered dietitian is an expert in nutrition and growth of babies and children.

### **FEEDING**

- Watch how your baby acts during feedings.
- If your baby has difficulty eating, it may be helpful to change your baby's position and/or lessen the noise, activity and light in the room.
- It is important to talk with your child's primary health care provider about any problems your child is having with feeding.

### **REFLUX**

Talk to your baby's primary health care provider if your baby shows one or more of the following signs:

- spits up often
- refuses to eat or eats only small amounts
- cries and seems in pain during and after feedings — arching of the back may be a sign of discomfort
- chokes or gags
- has breathing problems — wheezing, coughing, congestion
- has poor weight gain

## **Who Can Help?**

- Your child's **Primary Health Care Provider**
- A **Public Health Nurse**
- A pediatric **Registered Dietitian**
- A pediatric **Speech and Language Pathologist**
- A pediatric **Occupational Therapist**
- A pediatric **Physical Therapist**
- A **Lactation Consultant**
- A pediatric **Gastroenterologist**
- **WIC**, a special supplemental nutrition program for Women, Infants and Children
- **Healthy Mothers/Healthy Babies**, a toll-free referral service (1-800-322-2588)



# Behavior and Social Skills

## *Infancy*

### What Parents Should Know

Low birth weight babies may be especially sensitive to sounds, lights, and being touched. Your baby's behavior will tell you a lot about how he is coping with the world around him. Parents can help by learning what their baby's behaviors mean.

Your baby may be showing that he is happy or content if he:

- is quiet, awake, alert
- looks relaxed
- is able to make eye contact

Your baby may be unhappy, uncomfortable or upset if he:

- cries or is fussy
- stiffens or arches his neck or back
- spits up
- has changes in skin color (becomes blue, mottled or pale)
- startles frequently

Each baby is a unique person. It is important for parents and caregivers to watch closely so that they can recognize the baby's unique messages and cues. When children receive warm, responsive, loving care, they are more likely to feel safe and secure.

### What Parents Can Do

- Be loving and responsive.
- Cuddle, rock, talk, smile and sing.
- Watch your baby closely to know when he is ready for play or ready for rest.
- Pick up and comfort your baby when he is crying.
- Protect your baby from lights, sounds, and handling that he does not like.
- Learn how to hold and move your baby in ways that support his head and body.
- Gently offer your baby sights and sounds he likes.
- Try to have a feeding and playing schedule that is right for your baby.
- Plan bathing, feeding, and play times when your baby is not too tired or stressed.

To soothe your baby and help him sleep:

- Hold and snuggle him
- Allow him to suck
- Take him for a walk in the stroller
- Carry him close to your body
- Rock him gently
- Pat him gently with rhythm
- Sing to him
- Give him a bath

If your baby is having trouble sleeping, or is hard to comfort, talk with his primary health care provider.

## *Early Childhood*

### What Parents Should Know

As children grow, they are learning to live in the world around them. New experiences can be confusing and frustrating. Low birth weight children may show us that they are having trouble by their behavior. Observe your child to see if he is:

- very irritable
- overly sensitive to touch, sounds or movement
- too aggressive or unassertive
- unusually anxious or worried about new situations
- extremely shy
- having trouble sleeping

### What Parents Can Do

- Be loving and responsive to your child.
- Cuddle, rock, talk, smile, and sing to him.
- Provide routine.
- Redirect activities. (Don't overuse the word "NO").
- Provide safe, child friendly areas for play.
- Play with your child.
- Read to your child.
- Consider if your child is hungry, tired or over-stimulated by his surroundings.

If you have concerns about your child's behavior or social skills, talk with his Primary Health Care Provider.

### Who Can Help?

- Your child's **Primary Health Care Provider**
- A **Developmental Pediatrician**
- A pediatric **Occupational Therapist**
- A pediatric **Physical Therapist**
- A **Psychologist**
- A **Public Health Nurse**
- An **Early Education Teacher**
- A **High Risk Infant Follow-up Clinic**
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Vision



## What Parents Should Know

- Retinopathy of prematurity (ROP) is an eye disease that occurs in some babies born early or small. ROP is *not* usually a problem for babies born less than twelve weeks early or who weighed three pounds, three ounces or more at birth. Babies born twelve or more weeks early or weighing three pounds, three ounces or less at birth will have an eye exam before or soon after leaving the hospital. An ophthalmologist who has experience working with babies and young children should do this exam.
- Babies with ROP need to have their eyes checked regularly for any changes and to determine if treatment is needed. This may be as often as once a week for a short period of time. Appointments may continue after discharge from the hospital. Your baby's ophthalmologist will talk with you about how frequently your baby needs to be seen.
- Although more common in babies who had ROP, the following eye problems may occur in any low birth weight baby:
  - Poor vision (especially near-sighted)
  - Inward or outward turning of one or both eyes (“wandering or lazy eye”)

**Your child's eyes or vision should be checked (for babies born twelve or more weeks early or weighing three pounds, three ounces or less):**

- before leaving the hospital or between four to six weeks after birth by pediatric ophthalmologist
- by the primary health care provider at well baby/child checks
- as recommended by the ophthalmologist (generally at one year adjusted age and when the child starts school)



## What Parents Can Do

Observe your baby:

- to make sure he is using his eyes to follow your face (by six weeks adjusted age)
- for eyes that cross after three months adjusted age (one or both eyes)
- for excess redness or tearing

Talk with your baby's primary health care provider if you have any concerns about your child's eyes or vision.

## Who Can Help?

- Your child's **Primary Health Care Provider**
- A pediatric **Ophthalmologist**
- A **Public Health Nurse**
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Hearing

## What Parents Should Know

- Babies learn to talk by hearing other people talk. It is important to find out as soon as possible if an infant has a hearing problem. Early identification of hearing difficulties can make a big difference in helping the infant learn to talk.
- **All babies should have a hearing test before three months of age.** It is especially important for low birth weight babies to be tested. Hearing loss occurs in about 2 out of every 100 children who were born at low birth weight. Many hospitals test hearing before babies go home.

## What Parents Can Do

- **It is very important to know if your baby has passed a hearing test.** If your baby has not passed a hearing test, be sure to follow up with a hearing specialist (a pediatric audiologist). If your baby has a hearing loss, get advice from your primary health care provider or audiologist as early as possible.
- Observe your baby. A baby with hearing loss may make cooing sounds and then not progress. Babies should say consonant sounds (“ba,” “ma,” “da,” etc.) at 6 to 8 months *adjusted age*.
- Children with hearing loss may use their eyes very well. Sometimes it will seem that a child is hearing when she is actually responding to what she sees. Watch for her response to sounds including those out of her sight.
- Children may develop a hearing loss after the early months of life. Talk with your child’s primary health care provider if you have any concerns about how well your child is hearing at any age.

### **Hearing should be tested or re-tested:**

- Before three months of age
- If she has not passed a hearing test
- If you are concerned that your baby/child may not be hearing
- If your child is behind on his talking development or has stopped talking or stopped making new sounds and words.
- As recommended by your baby’s primary health care provider

## Who Can Help?

- Your child’s **Primary Health Care Provider**
- A pediatric **Audiologist**
- A **Public Health Nurse**
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Talking and Understanding

## What Parents Should Know

- Learning to communicate begins at a very early age. From early on, your baby listens to the sounds you make and watches your face.
- A baby's first sounds are "cooing" (aah, ooh), then consonant sounds (ba, ga, ma, da). Next a baby babbles (baba, gaga, mama, dada). Babies like it when adults repeat the sounds the baby is making. As the baby grows he will try to copy the facial expressions and sounds the adult is making.
- By one year of age, a child can say two to three words with meaning. By two years of age, a child can put two or more words together in simple sentences and has a vocabulary of about 300 words. A three year old says four or five word sentences and has a vocabulary of about 900 words.
- Children who were born at low birth weight are at higher risk for speech and language problems. These problems may include having difficulty talking or understanding what is said to him.
- Speech and language skills should be monitored by your primary health care provider and tested by developmental specialists when needed (at approximately 18 to 36 months of age).

## What Parents Can Do

- Remember to use *adjusted age* when comparing your child's progress with developmental language charts.
- Talk with your child's primary health care provider if you have concerns about your child's language skills.
- A delay in talking and understanding may indicate a hearing loss. Any child with delayed speech and language skills should have a hearing test. Talk with your child's primary health care provider.
- Encourage early language development by:
  - talking and singing while you are dressing, feeding, or playing with your baby
  - responding to and repeating back the sounds your baby makes
  - talking to your baby about what she is looking at or doing
  - reading out loud to your child every day

## Who Can Help?

- Your child's **Primary Health Care Provider**
- A **Developmental Pediatrician**
- A pediatric **Audiologist**
- A pediatric **Speech and Language Pathologist** (speech therapist)
- A **High Risk Infant Follow-up Clinic**
- An **Early Intervention Center** (Birth to Three Program)
- A **Public Health Nurse**
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Learning

## What Parents Should Know

- Watching the baby as he learns to talk and socialize (smiling, recognizing family in the household etc.) tells us about his early thinking and learning skills. Your baby also shows that he is learning when he looks around, listens to sounds, reaches for things he wants and enjoys playing.
- New experiences contribute a lot to learning. As he gets older, your child should continue to show new skills and abilities.
- Significant problems with the ability to learn can begin to be seen by 18 to 24 months.
- For some babies and children, it might be very helpful to work with a teacher and/or therapist who can help provide experiences for your baby/child to learn.
- Testing for learning skills is recommended for **very low birth weight** babies (less than three pounds, three ounces) when they are 36 to 48 months old.

## What Parents Can Do

Parent interaction is vital in helping babies learn new skills.

- Be loving and responsive to your child.
- Respond to your child's cues.
- Establish routines and rituals.
- Encourage safe exploration and play.
- Offer age-appropriate toys.
- Talk, read, and sing to your child.
- Minimize TV watching, choose TV shows carefully, and watch with your child.
- Use discipline as an opportunity to teach.
- Choose quality childcare and stay involved.
- Recognize that each child is unique.
- Enroll your infant/child in early intervention services, if recommended.

*Some suggestions taken from I Am Your Child Foundation's "Promoting Young Children's Healthy Development and School Readiness: Ten Guidelines"*

## Who Can Help?

- Your child's **Primary Health Care Provider**
- A **Developmental Pediatrician**
- A **Family Resources Coordinator**
- A **High Risk Infant Follow-up Clinic**
- A pediatric **Psychologist**
- Early Education **Teacher**
- **Early Intervention Centers** (Birth to Three Programs)
- A **Public Health Nurse**
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Motor Skills

## What Parents Should Know

Parents watch eagerly for their children to use their hands, roll over, crawl, sit, and take first steps. Development of motor skills depends on your baby's health, nutrition and brain development.

- Be sure to consider *adjusted age* when watching for the development of motor skills.
- While most low birth weight babies do well, these babies are more likely than other babies to have problems coordinating movement during their first years. Your baby's primary health care provider will check your child's muscle tone, strength, coordination, and movement skills at well-child checks.
- Your primary health care provider may recommend evaluation of your baby's motor development, by a developmental specialist such as a pediatric physical or occupational therapist.
- When serious motor problems continue, a diagnosis of cerebral palsy may be considered. Cerebral palsy means there has been an injury to the brain that makes it difficult to coordinate movement. Cerebral palsy ranges from very mild to severe.

**Your baby's motor skills should be monitored at well baby/child visits with special attention:**

- Between four and six months adjusted age
- Between eight and 12 months adjusted age
- Between fifteen and 18 months adjusted age





## What Parents Can Do

- Use your baby's *adjusted age* when comparing his progress to developmental charts.
- Have regular checks of your baby's motor skills during his first few years of life.
- Talk with your primary health care provider about follow-up clinics or programs near your home that provide regular developmental screening or evaluations of infant and toddler motor skills.
- Make sure your baby spends some supervised playtime on her tummy and in other positions every day. (Place your baby on her back to sleep).
- Limit use or avoid jumping seats, baby walkers and Exersaucers. Babies who use walkers are at risk for injury. Instead, give your baby plenty of time to play on the floor in a safe place.
- Provide a safe environment so your child can move and play.
- Sometimes differences in muscle tone may resolve on their own, other times they don't. Therapy from a pediatric occupational or physical therapist may be very helpful.
- Discuss any concerns you have with your baby's primary health care provider.

## Who Can Help?

- Your child's **Primary Health Care Provider**
- A **Developmental Pediatrician**
- A **High Risk Infant Follow-up Clinic**
- A pediatric **Occupational Therapist**
- A pediatric **Physical Therapist**
- A **Family Resources Coordinator**
- A **Public Health Nurse**
- **Early Intervention Centers** (Birth to three programs)
- **Healthy Mothers/Healthy Babies** (1-800-322-2588)

# Parent and Family Support

## What Parents Should Know

- Parenting a low birth weight infant and child will give you many joyful and tender moments. Parenting a low birth weight infant and child can also be stressful.
- Low birth weight babies frequently go home from the hospital with continuing health issues and concerns. Parents often experience worry, financial strain, physical and emotional exhaustion, and difficult family interactions.
- Help will often be offered to you before your baby leaves the hospital. This might be a referral to a public health nurse, information about a parent support group, or a list of resources that can help. Don't hesitate to accept a referral or a telephone number.

## What Parents Can Do

- Be sure to have a clear understanding of your baby's health and care needs at the time of hospital discharge. Ask for more information if you need it.
- Know how to contact your baby's primary health care provider if you have questions regarding your baby's health.
- Talk with your child's primary health care provider. S/he can listen, offer suggestions, and help you get in touch with people or groups that can help. Talk with your primary health care provider about how his/her office provides a "medical home". See page 16 for more on "Medical Home."
- Know what signs and symptoms need emergency care. Know the telephone number and location of emergency services.
- Before a visit to your child's primary health care provider or specialist, write down questions that you want to ask.
- At the appointment, take notes and get copies of records whenever possible.
- Consider inviting another adult to come to the appointment with you. It can be helpful to have more than one person listening to what the primary health care provider tells you.
- A *Care Notebook* or *Care Organizer* can help you organize information about your child. Families in Washington State can receive a free care notebook (available in English) or an organizer (available in several languages) by calling 1-800-826-9873 or 206-622-0384. Southwest Washington families may receive a free care notebook (available in English only) by calling 253-403-5525.

## **Who Can Help?**

- **A Primary Health Care Provider**
- **A Social Worker**
- **A Family Resources Coordinator**
- **A Family Counselor**
- **A Public Health Nurse**
- **Children with Special Health Care Needs (CSHCN) program RN**
- **A Parent Support Group**
- **Healthy Mothers/Healthy Babies (1-800-322-2588)**



# Medical Home

A Medical Home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost effective manner. Children and their families who have a medical home receive the care they need from a pediatrician or physician (pediatric health care professional) whom they trust. The pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential.

The American Academy of Pediatrics believes that all children should have a medical home where care is:

## *Accessible*

- Care is provided in the child's community.
- All insurance, including Medicaid, is accepted and changes are accommodated.

## *Family-Centered*

- The family is recognized as the principal caregiver and the center of strength and support for children.
- Unbiased and complete information is shared on an ongoing basis.

## *Continuous*

- The same primary pediatric health care professionals are available from infancy to adolescence.
- Assistance with transitions (to school, home, adult services) is provided.

## *Comprehensive*

- Health care is available 24 hours a day, 7 days a week.
- Preventative, primary, and tertiary care needs are addressed.

## *Coordinated*

- Families are linked to support, educational, and community-based services.
- Information is centralized.

## *Compassionate*

- Concern for the well being of child and family is expressed and demonstrated.

## *Culturally Effective*

- Family's cultural background is recognized, valued and respected.



**When we asked a parent, “What does a medical home mean to you?”, this was the response:**

**“It is my relationship based on trust with my child’s pediatrician. I can get medical attention for my son 24 hours a day, by either his doctor, the clinic’s doctor on call, or by being referred to the emergency department if needed.**

**When my son needs special services, we get referred in a timely manner. The partnership that I have with our son’s doctor is based on trust, and we acknowledge and respect both our strengths and weaknesses. Our doctor’s office also helps us to get connected with community resources or services that help our family.**

**Best of all, our doctor treats us as a family — not just focusing on our child, but asks about how all of us are doing, and I really like that. I would recommend that every family talk to their provider about participating in the medical home concept.”**

*— Parent (King County)*

## GLOSSARY

### PROGRAMS AND PROFESSIONALS WHO CAN HELP

**Audiologist** – a specialist in testing hearing and treating hearing loss.

**Children with Special Health Care Needs (CSHCN) program** – a program, through the Washington State Department of Health, in which nurses help families obtain health care and other needed community services.

**Developmental Pediatrician** – a doctor who specializes in infant and child development.

**Family Counselor** – helps families and individuals cope with personal stress and life issues.

**Family Resources Coordinator** – helps families concerned about their child’s development to find and coordinate assessment, evaluation, early intervention, and community services. Serves children from birth to three years of age.

**Gastroenterologist** – a doctor who specializes in digestive conditions and diseases.

**Healthy Mothers/Healthy Babies** – a program that helps Washington State families find community services, such as Family Resources Coordinators and Children with Special Health Care Needs nurses.

**High Risk Infant Follow Up Clinic** – provides multidisciplinary developmental assessments for infants and children at risk for developmental delay.

**Lactation Specialist** – a professional who helps mothers with breast-feeding issues.

**Occupational Therapist** – a specialist who evaluates and treats motor skills, play skills and sensory skills. Some occupational therapists also assess and treat feeding problems.

**Ophthalmologist** – a doctor who specializes in treating conditions and diseases of the eye.

**Parent Support Group** – a group of parents having similar life issues.

**Physical Therapist** – a specialist who evaluates and treats joint alignment, muscle coordination, movement and positioning problems. Some physical therapists also evaluate feeding skills and provide therapy for feeding problems.

**Primary Health Care Provider** – a doctor or nurse practitioner who provides health care management and well-child care.

**Psychologist** – a specialist in cognitive and behavioral development.

**Public Health Nurse** – a registered nurse, working at a public health department, who assesses health needs, provides information about health, and helps find local health services.

**Registered Dietitian** – a specialist in nutrition and growth.

**Social Worker** – a professional who helps families with resources needed for daily living.

**Speech and Language Pathologist** – a specialist in speech and language development and treatment. Some speech and language pathologists also assess and treat feeding problems.

**Teacher (early education)** – a specialist in the learning skills of infants and children from birth to three years of age.

**WIC** – a special supplemental nutrition program for Women, Infants and Children.

## RESOURCES

### Where to begin

- If you have a concern about your child's development, talk to your primary health care provider (doctor or nurse practitioner),
- and/or call Healthy Mothers, Healthy Babies at 1-800-322-2588, who will connect you with a Children with Special Health Care Needs Nurse, and/or a Family Resources Coordinator in your area who can help you find resources and support for you and your child.

### Prematures:

- *Preemies – The Essential Guide for Parents of Premature Babies*  
Wechsler, Linden D.; Trenti, Paroli E.; and Wechsler, Doron M.; Pocket Books: New York, 2000.
- *Your Premature Baby and Child – Helpful Answers and Advice for Parents*  
Tracy, Amy E.; Maroney, Dianne I.; with Bernbaum, Judy C.; and Groothuis, Jessie R.; Berkley Books: New York, 1999.
- American Association for Premature Infants: 513-522-8040; <http://aapi-online.org/>
- Premie-L: [www.premie\\_l.org](http://www.premie_l.org)

### Nutrition Resources:

- *How to Get Your Kid to Eat...But Not Too Much*  
Satter, Ellyn. Bull Publishing: 1987.
  - *Child of Mine, Feeding with Love and Good Sense*  
Satter, Ellyn. Bull Publishing: 2000.
- These books are available in most bookstores or contact Bull Publishing: 800-676-2855; [www.bullpub.com](http://www.bullpub.com)
- Gaining and Growing - Assuring Nutritional Care of Preterm Infants: <http://staff.washington.edu/growing/index.html>

### Behavior:

- *The Fussy Baby Book: Parenting Your High-Need Child from Birth to Age Five*  
Sears, W.; and Sears, M.; Little Brown and Co.: 1996
- [www2.medsch.wisc.edu/childrenshosp/parents\\_of\\_preemies/behaviorprobs.html](http://www2.medsch.wisc.edu/childrenshosp/parents_of_preemies/behaviorprobs.html)

### Speech/Hearing:

- American Speech-Language-Hearing Association (ASHA): [www.asha.org](http://www.asha.org)
- [www2.medsch.wisc.edu/childrenshosp/parents\\_of\\_preemies/hearing.html](http://www2.medsch.wisc.edu/childrenshosp/parents_of_preemies/hearing.html)
- Washington Sensory Disabilities Services: 800-572-7000; [www.wsdsonline.org](http://www.wsdsonline.org)

### Learning:

- Washington State Governor's Commission on Early Learning: [www.earlylearningofwa.org](http://www.earlylearningofwa.org)
- Zero to Three: [www.zerotothree.org](http://www.zerotothree.org)

### Vision:

- [www2.medsch.wis.edu/childrenshosp/parents\\_of\\_preemies/rop.html](http://www2.medsch.wis.edu/childrenshosp/parents_of_preemies/rop.html)
- [www2.medsch.wis.edu/childrenshosp/parents\\_of\\_preemies/latereye.html](http://www2.medsch.wis.edu/childrenshosp/parents_of_preemies/latereye.html)
- Blind Children's Center: 800-222-3566; [www.blindchildrenscenter.org](http://www.blindchildrenscenter.org)
- National Association for Parents of the Visually Impaired: 800-562-6265; [www.spedex.com/napvi](http://www.spedex.com/napvi)

**RESOURCES** *continued from previous page***Parent and Family Support:**

- Washington State Parent to Parent: 206-565-2266 (v/tty) or 800-5-PARENT (v/tty); [www.washingtonpave.com/](http://www.washingtonpave.com/)
- Washington State Fathers Network: 425-747-4004 ext. 218 or 206-284-2859; [www.fathersnetwork.org/web/news/main/wsfm.html](http://www.fathersnetwork.org/web/news/main/wsfm.html)
- Ethnic Outreach and Parent Support: 800-821-5927
- Parent to Parent Power (Serving Asian Parents): 253-531-2022

**STATE AGENCIES AND PROGRAMS****Children with Special Health Care Needs Program**

Washington Department of Health  
Maternal and Child Health/Community and Family Health  
360-236-3571

**Division of Developmental Disabilities (DDD)**

360-902-8444 State Program Office  
800-321-2808 (Washington State Operator for the connection to the regional office nearest you)

**Public Health Nurses**

(State, District or County Level)  
Office of Health Consumer Assistance  
800-535-0127

**Infant Toddler Early Intervention Program (ITEIP)**

*For children birth to three*  
(ITEIP is part of DSHS/DDD)  
360-902-8488

To locate the Family Resources Coordinator in your local area, call 800-322-2588 (ASK Line – Healthy Mothers/Healthy Babies) or go to their website, [www.wa.gov/dshs/iteip/iteip.html](http://www.wa.gov/dshs/iteip/iteip.html)

**Neurodevelopmental Centers and Developmental Centers**

Call your primary health care provider or ITEIP 360-902-8490

# GUIDE FOR HEALTH AND DEVELOPMENTAL MONITORING

Evaluation should be considered in all areas whenever there is concern.

|  |   |
|--|---|
| <b>GROWTH</b> (WEIGHT, LENGTH, HEAD MEASUREMENT) | Evaluation at each visit to the primary health care provider's office   |
| <b>NUTRITION/FEEDING</b>                         | Assessment at each visit to the primary health care provider's office   |
| <b>HEALTH</b>                                    | Examination at each visit to the primary health care provider's office  |
| <b>VISION</b>                                    | Assessment at well-baby/child visits <ul style="list-style-type: none"><li>• If born under 28 weeks and 3 pounds, 3 ounces, should have examination by ophthalmologist before discharge from the hospital or shortly thereafter. The ophthalmologist will make recommendations for further follow up.</li><li>• Examination with ophthalmologist should be scheduled any time there are concerns about sight, eye tracking, eyes crossing or other eye/vision concerns.</li></ul> |
| <b>HEARING</b>                                   | Assessment at well-baby/child visits <ul style="list-style-type: none"><li>• Hearing should be tested within the first three months of life (if not tested before discharge).</li><li>• Hearing should be closely monitored and re-checked if hearing test is not passed or for any concerns.</li><li>• Hearing should be monitored for later hearing loss in babies and children with specific risk factors. (Talk with your baby's primary care provider).</li></ul>            |
| <b>MOTOR/MOVEMENT</b>                            | Assessment at well-baby/child visits <ul style="list-style-type: none"><li>• Movement assessments at four months to six months, 8 to 12 months, 15 to 18 months adjusted age.</li><li>• Additional evaluations based on individual needs.</li></ul>   |
| <b>LANGUAGE</b>                                  | Assessment at well-baby/child visits <ul style="list-style-type: none"><li>• Observation of typically emerging language milestones.</li><li>• Test hearing if delay or regression noted.</li><li>• Screenings at approximately 18 and 36 months adjusted age.</li></ul>   |
| <b>LEARNING</b>                                  | Assessment at well-baby/child visits <ul style="list-style-type: none"><li>• Observation may begin around 6 months adjusted age.</li><li>• Standardized cognitive assessment recommended at approximately 36 to 48 months of age for the very low birth weight child or for concerns.</li></ul>   |
| <b>BEHAVIOR/TEMPERAMENT</b>                      | Assessment at well-baby/child visits  |



Mary Bridge Children's Hospital  
& Health Center

MultiCare 

