



Developmental Follow-Up of High Risk Newborns

Indiana Perinatal Quality Improvement Collaborative
System Implementation Committee

2015

Endorsed by the IPQIC Governing Council

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Overview

In *Coordinated Perinatal Systems of Care* endorsed by the Governing Council in May 2014, eight specific roles¹ were identified for hospitals and their affiliate hospitals wishing to be identified as a Perinatal System. One of the identified roles was NICU Transition to Home and Follow-up. The High Risk Follow-up Subcommittee of the System Implementation Committee was charged with the following activities:

- Review national guidelines, current practices from other states, relevant literature and identify promising/best practices for following high risk infants after discharge from NICU;
- Determine the cohort of high risk newborns that need to be followed;
- Recommend guidelines for follow-up methods based upon best practices; and
- Define indicators, benchmarks, and process measures to evaluate follow-up programs for high risk infants

While each Perinatal System was charged with the responsibility for the following activities: Retinopathy of Prematurity (ROP) Screening; implementation of a developmental clinic for high risk newborns; and assistance in accessing pediatric subspecialty care as needed, the cohort of children to be followed, the periodicity of screening and the screening tool to be used had to be determined.

The committee members began their work with a review of the existing literature. The most cited and definitive document was *Follow-Up Care of High-Risk Infants* published by the American Academy of Pediatrics. The paper was developed as a result of a 2002 workshop sponsored by the National Institute of Child Health and Human Development, National Institute of Neurologic Disorders and Stroke, and the Centers for Disease Control and Prevention. The paper concluded that "There are currently no standardized guidelines for the provision of follow-up services for high-risk infants in tertiary care centers despite the requirement for follow-up clinic experience in the 97 approved neonatal fellowship

¹ Perinatal Conferences, Training for Affiliate Hospitals, Quality Assurance, Support Services, Maternal-Fetal and Neonatal Transport, Post Partum and Interconception Care, NICU Transition and Follow-up, Interfacility Agreements

training programs in the United States and the increasing number of centers participating in multicenter networks."² The paper identified the need to improve standardization, comparability and data collection within and among centers. There was general agreement that neurodevelopmental outcomes for the identified cohort of infants be systematically monitored. This paper addressed the benefits of neonatal follow-up, the population that should be followed, the periodicity of follow-up, tools to be used, finance issues and the role of the community physician. These components served as a road map for the activities of the subcommittee.

Cohort to be served

"Infants should receive follow-up assessments based on the severity of the perinatal problems, the interventions received in the NICU, the demographic risk factors of the infants' families, the outcome profile of the cohort in the individual NICU, and the NICU's resources. ... There is increased recognition of the potential disconnect between perinatal outcomes and long-term outcomes"³

The charge of the subcommittee was to identify the cohort of infants that Perinatal Centers would be responsible for engaging in the follow-up program. In trying to develop a set of statewide guidelines, it was important to start with a group of infants that everyone can follow. While Perinatal Centers could add infants with other diagnoses to the cohort, the committee members were very conscious of the reality that financial support for follow-up programs is very limited and therefore were cautious in the identification of infants to be followed. Since funding will remain an issue for follow-up programs, limiting numbers of children required to be followed through more restrictive gestational age and weight criteria will be more economically feasible. The goal was to address those infants with the highest risk of neurodevelopmental delay currently supported by the literature. There was general recognition that children with complex medical conditions would be receiving ongoing assessment and treatment from multiple specialists. The cohort of infants that the committee is recommending be followed is identified in Table 1.

² Pediatrics Vol 114 No. 5 November 2004

³ Ibid

Table 1: Cohort of High Risk Infants to be Followed

<p>General:</p> <ul style="list-style-type: none"> • Less than 1001 grams • Less than 28 weeks gestational age • Triplets & Quadruplets (irrespective of gestational age) • Major Surgery (other than those listed below) • End-Stage Renal Failure • Neonatal Abstinence Syndrome Requiring Medical Therapy • Documented Bacterial or Fungal Sepsis • Meningitis/Osteomyelitis 	<p>Pulmonary</p> <ul style="list-style-type: none"> • O2 Dependency at 36 weeks Corrected Gestational Age • Tracheostomy • Congenital Diaphragmatic Hernia w/ or w/o ECMO • Inhaled Nitric Oxide Therapy • ECMO Therapy • Chylothorax 	<p>Gastro-intestinal</p> <ul style="list-style-type: none"> • NEC requiring surgical intervention and/or with associated bacterial SEPSIS • Isolated Bowel Perforation requiring surgical intervention • Gastroschisis/Omphalocele/Malrotation • Short gut • Tracho-esophageal fistula <p>Neurologic</p> <ul style="list-style-type: none"> • Moderate/Severe HIE w/ or w/o Therapeutic Hypothermia • Grade 3 or 4 IVH w/ or w/o Post hemorrhagic Hydrocephalus • PVL • Seizures Documented with EEG and/or aEEG <p>Cardiac</p> <ul style="list-style-type: none"> • PDA requiring surgical intervention • Isolated Congenital Heart Disease
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Screening Tool and Periodicity

As cited in Pediatrics, it is not realistic to expect all NICUs to support a comprehensive follow-up program because of limited resources, both personnel and finances. In addition, the subcommittee was committed to a process that would involve the family and their child's medical home.

Screening Tool

The recommended tool is the Ages and Stages Questionnaire (ASQ). The ASQ is an easy to administer questionnaire that can be completed by the family or could be administered by the medical home during routine visits. The ASQ has been in use for over 15 years and is considered highly reliable and valid. ASQ is a series of questionnaires designed to screen the developmental performance of young children in the areas of communication, gross

motor skills, fine motor skills, problem-solving, personal-social skills and overall development. The age appropriate scale is completed by the parent or caregiver. Each questionnaire looks at the strengths and challenges of the child and educates parents about their child's developmental milestones. The questionnaires take approximately 10-20 minutes to complete and are available in English, French, Korean and Spanish. The questionnaires can be administered in an online format or by paper and pencil. There is no minimum degree or license requirement to administer the scale. ⁴ Additional information about the ASQ is included in the Appendices.

Medical Home

The Regional Perinatal Center should foster a relationship with the Primary Care Physician of each infant. An agreement with the medical home should be established upon discharge of the infant from the NICU regarding the administration and reporting of the ASQ results. Should the medical home be unable to participate in the administration of the ASQ the perinatal center should facilitate the completion of the questionnaire. Results should be shared between the center and the PCP with any recommended interventions done at a local level.

Periodicity

The committee has recommended that the age appropriate ASQ questionnaire be administered at 4, 9, 12, 18 and 24 months, adjusted for prematurity. This is aligned with the national practice of ending these follow-along programs at 24 months adjusted age.

Next Steps

The committee has two remaining issues to address:

- 1) *Define indicators, benchmarks and outcome measures to evaluate newborn follow-up programs for high-risk infants.*

⁴ <http://www.cebc4cw.org/assessment-tool/ages-and-stages-questionnaire/>

The development Data elements that would be required to evaluate the effectiveness of the follow-up programs in terms of participation and linkage to community resources will need to be defined.

2) Recommend guidelines for referral to appropriate community resources.

Community resources will vary across the state and linkages to other family organizations will need to be included. The connection to community resources outside of traditional medicine (such as housing, education, social support), is an opportunity for innovation and new partnerships in the community. One concept that has shown promise is linking families to home visiting programs that are specifically tailored to their needs and are connected to local resources. Nurse-Family Partnership is an evidence-based home visiting program that follows a first-time, high-risk mom from less than 28-weeks' gestation through the target child's second birthday. Other home visiting programs and early start programs have great potential to change the outcome trajectory upward. Federal programs such as Early Head Start and Part C early intervention programs also may provide resources but varying eligibility criteria and resources may limit access to the services.

Appendix A: ASQ Screening Toolkit

Links to 15 FREE checklists, charts, & more!

Your Developmental Screening Toolkit

Tips & Tools for Informing Families and Improving Your Screening Program



VIEW THIS TOOLKIT ONLINE for easy linking to the resources:
www.brookespublishing.com/developmental-screening-toolkit



www.agesandstages.com | 1-800-638-3775





As an early childhood professional, you know how comprehensive developmental screening can improve lives and outcomes for children and

families. But to parents, screening can sometimes be a source of fear and anxiety—especially if they're not sure their child is reaching key milestones.

How can you help?

Arm parents with the knowledge they need: about their child's development *and* the critical importance of periodic developmental screening.

This toolkit makes it easy, with links to fact sheets, checklists, posters, and charts that educate families about key milestones and get them on board with developmental screening. You'll also find resources geared toward professionals, to help you improve your screening program and work effectively with families. Share these free resources today—and help ensure that more children are screened early for delays and connected with services that make all the difference.

Turn the page for free resources on screening & child development!

6 things every parent should know about developmental screening

- **It identifies delays early**, when interventions can help the most.
- **It helps ensure better futures.** Studies show* that children who receive early treatment for developmental delays are more likely to graduate from high school, hold jobs, and live independently.
- **It's recommended by the AAP.** The American Academy of Pediatrics recommends that *all* infants and young children be screened for delays as a regular part of their ongoing health care.
- **It helps parents take an active role in guiding child development.** Using a parent-completed screener like ASQ gives parents a chance to share their unique insights about their child and learn more about key developmental milestones.
- **It boosts parent-child bonding.** Parent-completed screenings are a great bonding experience for parents and children. (ASQ also offers fun and effective learning activities parents and children can do together between screenings.)
- **It's easy and quick.** Screening isn't a long, time-intensive process. It can be completed in many settings, from homes to a doctor's waiting room, and parents can fill out most screening questionnaires in under 15 minutes.

*Dunkle, M. (Fall 2004). High Quality Developmental Screening. *Developmental & Behavioral News*, 13(2).

Screening Resources



Developmental Screening Fact Sheet

In a friendly Q&A format, this one-page fact sheet gives parents a fast introduction to screening and child development. (In English and Spanish!)

http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/developmentalscreening.pdf



Public Awareness Poster

Print and hang this full-color poster in your office to remind parents why it's important to track developmental milestones and catch delays early.

http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/multiculturalflyer.pdf



Tips for Screening Success

How can your practice successfully implement a parent-completed screening tool? This article from the Brookes Early Childhood newsletter gives you 10 key tips, plus helpful free downloads to help you get started.

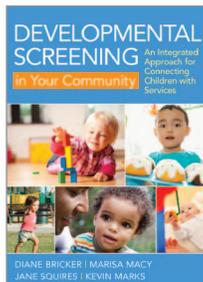
<http://archive.brookespublishing.com/articles/ec-article-0711.htm>



Tips on Working with Families

Parents are the most valuable partner in your screening program. In this newsletter article, the ASQ co-developers share practical tips and free downloads to help you partner with families and get them on board with your screening program.

<http://archive.brookespublishing.com/articles/asq-article-0513.htm>

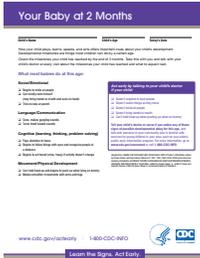


Book Excerpt from *Developmental Screening in Your Community*

Read this free excerpt from the new book by the co-developers of the trusted ASQ. You'll get a big-picture overview of 6 key components of a comprehensive, low-cost, community-wide early detection/Child Find system.

<http://archive.brookespublishing.com/documents/developmental-screening.pdf>

Child Development Resources



Developmental Milestones Checklists

With these parent-friendly checklists from the CDC, families will have a quick and easy way to check their child's progress toward important milestones and determine when to see a doctor with concerns. http://www.cdc.gov/ncbddd/actearly/pdf/checklists/all_checklists.pdf



Milestone Moments Booklet

The perfect quick-reference for parents, this colorful booklet is a great way to track child development from 2 months to 5 years and discover how to help them learn and grow. http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/milestonemomentseng508.pdf



“Your Child’s Early Development is a Journey”

Give parents a clear visual map of developmental milestones with this engaging, full-color handout. http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/trackchildsdevmilestoneseng.pdf



Child Growth Chart

Parents will love this growth chart! Customizable with photos of their child, it's a fun way to track physical growth *and* keep an eye on key milestones. http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/growthchart.pdf

ASQ Resources

The #1 screeners—ASQ-3™ for developmental screening and ASQ:SE for social-emotional screening—have been trusted for more than 15 years to pinpoint delays as early as possible. The parent-completed ASQ questionnaires are reliable and valid, cost effective, recommended by top organizations, and easy to administer and score. Learn more about ASQ in the free downloads below, and see www.agesandstages.com for more.

RESOURCES FOR PARENTS

ASQ-3 At a Glance

Fast facts about the ASQ-3 developmental screener. <http://agesandstages.com/asq-products/asq-3/asq-3-at-a-glance/>

ASQ-3 Overview

A concise, jargon-free one-sheet, perfect for parents who need a quick and clear introduction to ASQ-3.

In English: <http://agesandstages.com/pdfs/brief-overview-asq3-english.pdf>

In Spanish: <http://agesandstages.com/pdfs/brief-overview-asq3-spanish.pdf>

Free ASQ Screening

ASQ is part of the Easter Seals Make the First Five Count campaign! Parents can fill out a free ASQ questionnaire to see if their child's developmental progress is on track, and results will be mailed to them within two weeks. http://es.easterseals.com/site/PageServer?pagename=ntlc10_mffc_homepageasq

Free Activity Stickers

Share these fun and effective activity ideas with parents, and help them boost their child's development between screenings.

<http://agesandstages.com/asq-products/asq-3/asq-3-downloads/>

RESOURCES FOR PROFESSIONALS

ASQ Webinar

Led by the experts behind ASQ, this webinar shows you how to work with families from diverse backgrounds throughout the screening process. <https://www1.gotomeeting.com/register/885359448>

ASQ Tips for Pediatric Offices

Get practical tips on weaving ASQ into the workflow of a pediatric office. Includes specific roles and responsibilities for the nurse, receptionist, clinician, and other support staff. <http://www.agesandstages.com/pdfs/practical-clinic-aspects-v2.pdf>

Office Flow Procedures

This helpful flowchart outlines the whole process of successful developmental-behavioral surveillance, screening, and referral. <http://archive.brookespublishing.com/documents/Bricker-screening-algorithm.pdf>

ASQ Success Stories

ASQ is used in all 50 states and in countries around the world. Read four of the many success stories here, and discover how other programs used ASQ to improve the lives of children and families. <http://agesandstages.com/success-stories/>

ASQ PowerPoint

Fun superhero-themed presentation on implementing ASQ in a medical home setting. <http://archive.brookespublishing.com/documents/Brookes-Early-Interventioners-Assemble.pdf>

LEARN MORE ABOUT ASQ at agesandstages.com

Appendix B: Sample ASQ Questionnaire



Ages & Stages Questionnaires®

9 Month Questionnaire

9 months 0 days through 9 months 30 days



Please provide the following information. Use black or blue ink only and print legibly when completing this form.

Date ASQ completed: _____

DATE HERE

Baby's information

Baby's first name: _____ Middle initial: _____ Baby's last name: _____

Baby's date of birth: _____

If baby was born 3 or more weeks prematurely, # of weeks premature: _____

Baby's gender: Male Female

Person filling out questionnaire

First name: _____ Middle initial: _____ Last name: _____

Street address: _____

Relationship to baby:
 Parent Guardian Teacher Child care provider
 Grandparent or other relative Foster parent Other: _____

City: _____ State/Province: _____ ZIP/Postal code: _____

Country: _____ Home telephone number: _____ Other telephone number: _____

E-mail address: _____

Names of people assisting in questionnaire completion: _____

Program Information

Baby ID #: _____ Age at administration in months and days: _____

Program ID #: _____ If premature, adjusted age in months and days: _____

Program name: _____



9 Month Questionnaire

9 months 0 days
through 9 months 30 days

On the following pages are questions about activities babies may do. Your baby may have already done some of the activities described here, and there may be some your baby has not begun doing yet. For each item, please fill in the circle that indicates whether your baby is doing the activity regularly, sometimes, or not yet.

Important Points to Remember:

Notes:

- Try each activity with your baby before marking a response.
- Make completing this questionnaire a game that is fun for you and your baby.
- Make sure your baby is rested and fed.
- Please return this questionnaire by _____.

COMMUNICATION

	YES	SOMETIMES	NOT YET	
1. Does your baby make sounds like "da," "ga," "ka," and "ba"?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
2. If you copy the sounds your baby makes, does your baby repeat the same sounds back to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
3. Does your baby make two similar sounds like "ba-ba," "da-da," or "ga-ga"? (The sounds do not need to mean anything.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
4. If you ask your baby to, does he play at least one nursery game even if you don't show him the activity yourself (such as "bye-bye," "Peek-a-boo," "clap your hands," "So Big")?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
5. Does your baby follow one simple command, such as "Come here," "Give it to me," or "Put it back," without your using gestures?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
6. Does your baby say three words, such as "Mama," "Dada," and "Baba"? (A "word" is a sound or sounds your baby says consistently to mean someone or something.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
COMMUNICATION TOTAL				—

GROSS MOTOR

	YES	SOMETIMES	NOT YET	
1. If you hold both hands just to balance your baby, does she support her own weight while standing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
				
2. When sitting on the floor, does your baby sit up straight for several minutes without using his hands for support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
				

GROSS MOTOR

(continued)

3. When you stand your baby next to furniture or the crib rail, does she hold on without leaning her chest against the furniture for support?



YES	SOMETIMES	NOT YET	—
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. While holding onto furniture, does your baby bend down and pick up a toy from the floor and then return to a standing position?



<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

5. While holding onto furniture, does your baby lower himself with control (without falling or flopping down)?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

6. Does your baby walk beside furniture while holding on with only one hand?

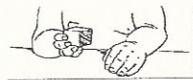
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

GROSS MOTOR TOTAL

—

FINE MOTOR

1. Does your baby pick up a small toy with only one hand?



YES	SOMETIMES	NOT YET	—
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Does your baby successfully pick up a crumb or Cheerio by using her thumb and all of her fingers in a raking motion? (If she already picks up a crumb or Cheerio, mark "yes" for this item.)



<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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3. Does your baby pick up a small toy with the tips of his thumb and fingers? (You should see a space between the toy and his palm.)



<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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4. After one or two tries, does your baby pick up a piece of string with her first finger and thumb? (The string may be attached to a toy.)



<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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5. Does your baby pick up a crumb or Cheerio with the tips of his thumb and a finger? He may rest his arm or hand on the table while doing it.



<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

6. Does your baby put a small toy down, without dropping it, and then take her hand off the toy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

FINE MOTOR TOTAL

—

*If Fine Motor Item 5 is marked "yes" or "sometimes," mark Fine Motor Item 2 "yes."

PROBLEM SOLVING

		YES	SOMETIMES	NOT YET	
1. Does your baby pass a toy back and forth from one hand to the other?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
2. Does your baby pick up two small toys, one in each hand, and hold onto them for about 1 minute?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
3. When holding a toy in his hand, does your baby bang it against another toy on the table?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
4. While holding a small toy in each hand, does your baby clap the toys together (like "Pat-a-cake")?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
5. Does your baby poke at or try to get a crumb or Cheerio that is inside a clear bottle (such as a plastic soda-pop bottle or baby bottle)?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
6. After watching you hide a small toy under a piece of paper or cloth, does your baby find it? (Be sure the toy is completely hidden.)		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
PROBLEM SOLVING TOTAL					—

PERSONAL-SOCIAL

		YES	SOMETIMES	NOT YET	
1. While your baby is on her back, does she put her foot in her mouth?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
2. Does your baby drink water, juice, or formula from a cup while you hold it?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
3. Does your baby feed himself a cracker or a cookie?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
4. When you hold out your hand and ask for her toy, does your baby offer it to you even if she doesn't let go of it? (If she already lets go of the toy into your hand, mark "yes" for this item.)		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
5. When you dress your baby, does he push his arm through a sleeve once his arm is started in the hole of the sleeve?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
6. When you hold out your hand and ask for her toy, does your baby let go of it into your hand?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
PERSONAL-SOCIAL TOTAL					—

OVERALL

Parents and providers may use the space below for additional comments.

1. Does your baby use both hands and both legs equally well? If no, explain:

 YES NO

2. When you help your baby stand, are his feet flat on the surface most of the time?
If no, explain:

 YES NO

3. Do you have concerns that your baby is too quiet or does not make sounds like other babies? If yes, explain:

 YES NO

4. Does either parent have a family history of childhood deafness or hearing impairment? If yes, explain:

 YES NO

5. Do you have concerns about your baby's vision? If yes, explain:

 YES NO

6. Has your baby had any medical problems in the last several months? If yes, explain:

 YES NO

OVERALL *(continued)*

7. Do you have any concerns about your baby's behavior? If yes, explain:

 YES NO

8. Does anything about your baby worry you? If yes, explain:

 YES NO