Developmental Follow-Up of High Risk Newborns

Indiana Perinatal Quality Improvement Collaborative
System Implementation Committee

Endorsed by the IPQIC Governing Council
April 30, 2015
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Overview

In *Coordinated Perinatal Systems of Care* endorsed by the Governing Council in May 2014, eight specific roles\(^1\) 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

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\(^1\) 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

<table>
<thead>
<tr>
<th>General</th>
<th>Pulmonary</th>
<th>Gastro-intestinal</th>
<th>Neurologic</th>
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<tr>
<td>• Less than 1001 grams</td>
<td>• O2 Dependency at 36 weeks</td>
<td>• NEC requiring surgical intervention</td>
<td></td>
</tr>
<tr>
<td>• Less than 28 weeks gestational age</td>
<td>Corrected Gestational Age</td>
<td>and/or with associated bacterial SEPSIS</td>
<td></td>
</tr>
<tr>
<td>• Triplets &amp; Quadruplets (irrespective of gestational age)</td>
<td>• Tracheostomy</td>
<td>• Isolated Bowel Perforation requiring surgical intervention</td>
<td></td>
</tr>
<tr>
<td>• Major Surgery (other than those listed below)</td>
<td>• Congenital Diaphragmatic Hernia w/ or w/o ECMO</td>
<td>• Gastrochisis/Omphalocele/Malrotation</td>
<td></td>
</tr>
<tr>
<td>• End-Stage Renal Failure</td>
<td>• Inhaled Nitric Oxide Therapy</td>
<td>• Short gut</td>
<td></td>
</tr>
<tr>
<td>• Neonatal Abstinence Syndrome Requiring Medical Therapy</td>
<td>• ECMO Therapy</td>
<td>• Tracho-esophageal fistula</td>
<td></td>
</tr>
<tr>
<td>• Documented Bacterial or Fungal Sepsis</td>
<td>• Chylothorax</td>
<td></td>
<td></td>
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<tr>
<td>• Meningitis/Osteomyelitis</td>
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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. 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.

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
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!
**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!)

**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.

**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.
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”

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


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/briefoverview_asq3_english.pdf
In Spanish: http://agesandstages.com/pdfs/briefoverview_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


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


LEARN MORE ABOUT ASQ at agesandstages.com

Your Developmental Screening Toolkit

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

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Appendix B: Sample ASQ Questionnaire
ASQ3 Ages & Stages Questionnaires®

9 months 0 days through 9 months 30 days

9 Month Questionnaire

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 gender: 
☐ Male   ☐ Female
If baby was born 3 or more weeks prematurely, # of weeks premature: ____________

Baby's date of birth: ____________________________

Person filling out questionnaire

First name: ____________________________
Middle initial: ____________
Last name: ____________________________
Relationship to baby: 
☐ Parent   ☐ Guardian   ☐ Teacher   ☐ Child care provider
☐ Grandparent or other relative
☐ Foster parent
☐ Other: ____________________________
Street address: ____________________________
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: ____________________________

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9 Month Questionnaire

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:
- 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 _____________.

Notes:

COMMUNICATION

1. Does your baby make sounds like “da,” “ga,” “ka,” and “ba”?

2. If you copy the sounds your baby makes, does your baby repeat the same sounds back to you?

3. Does your baby make two similar sounds like “ba-ba,” “da-da,” or “ga-ga”? (The sounds do not need to mean anything.)

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”)?

5. Does your baby follow one simple command, such as “Come here,” “Give it to me,” or “Put it back,” without your using gestures?

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.)

GROSS MOTOR

1. If you hold both hands just to balance your baby, does she support her own weight while standing?

2. When sitting on the floor, does your baby sit up straight for several minutes without using his hands for support?

COMMUNICATION TOTAL: ______

GROSS MOTOR TOTAL: ______
### 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:  
   - GROSS MOTOR TOTAL:  

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?  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - GROSS MOTOR TOTAL:  

5. While holding onto furniture, does your baby lower himself with control (without falling or flopping down)?  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - GROSS MOTOR TOTAL:  

6. Does your baby walk beside furniture while holding on with only one hand?  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - GROSS MOTOR TOTAL:  

### FINE MOTOR

1. Does your baby pick up a small toy with only one hand?  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

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.)  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

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.)  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

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.)  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

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.  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

6. Does your baby put a small toy down, without dropping it, and then take her hand off the toy?  
   - Yes:  
   - Sometimes:  
   - Not Yet:  
   - FINE MOTOR TOTAL:  

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

1. Does your baby pass a toy back and forth from one hand to the other?  

2. Does your baby pick up two small toys, one in each hand, and hold onto them for about 1 minute?  

3. When holding a toy in his hand, does your baby bang it against another toy on the table?  

4. While holding a small toy in each hand, does your baby clap the toys together (like "Pat-a-cake")?  

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)?  

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.)

PROBLEM SOLVING TOTAL

PERSONAL-SOCIAL

1. While your baby is on her back, does she put her foot in her mouth?  

2. Does your baby drink water, juice, or formula from a cup while you hold it?  

3. Does your baby feed himself a cracker or a cookie?  

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.)  

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?  

6. When you hold out your hand and ask for her toy, does your baby let go of it into your hand?  

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

   

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