

We Listened! Collaborative Development of a Newborn Screening Prenatal Fact Sheet



Presenters:

Linda Bowen, M.S., CCC-SLP, EHDI Regional Consultant
Morgan Moore, M.S., CCC-SLP, EHDI Regional Consultant

NC Division of Public Health
Children and Youth (C&Y) Branch
Early Hearing Detection and Intervention (EHDI) Program



Early Hearing Detection and Intervention (EHDI)
2018 Annual Meeting
Denver, Colorado
March 18 – 20, 2018

Learning Objectives

Participants will be able to:

- 1. Discuss the importance of engaging parents and key stakeholders in the development of EHDI educational materials.**
- 2. Describe features of accessible print materials.**
- 3. List the important components of an EHDI prenatal educational material.**

Importance of Partnering with Families

- Joint Committee on Infant Hearing
- Maternal and Child Health Bureau
- North Carolina Children and Youth (C&Y) Branch



Joint Committee on Infant Hearing 2013 Supplement to the 2007 Position Statement

Goal 8: Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels

EHDI program success depends on families working in partnership with professionals as a well-coordinated team.

JOINT COMMITTEE ON INFANT HEARING, Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., Brookhouser, P.E., Epstein, S., Buchman, C., Mehl, A., Vohr, B. Moeller, M. P., Martin, P., Benedict, B. S., Scoggins, B., Crace, J., King, M., Sette, A., & Martin, B. (2013). Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing. *Pediatrics*, 131(4), e1324-e1349. Retrieved from <http://pediatrics.aappublications.org/content/131/4/e1324>

Maternal and Child Health Bureau

The Title V MCH Services Block Grant Guidance, has defined family/consumer partnership as “the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course.

Family engagement reflects a belief in the value of the family leadership at all levels from an Individual, community and policy level.”



NC C&Y Branch Family Engagement Philosophy

- **Build and maintain relationships with families to ensure Branch programs and services are family-centered.**
- **Recognize and respect the knowledge, skills and expertise that families possess.**
- **Assure that family members are actively engaged in program planning, implementation and evaluation.**



Where We Started

Photo credit: C&Y Branch

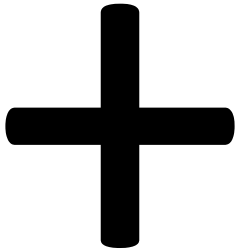


Photo credits: C&Y Branch

Listen to Parents



Photo credit: C&Y Branch

- **Ask** parents who have experienced the hearing loss journey what their ideas are for improving the system.
- **Listen** to the experiences and the ideas of parents. They are the experts!
- **Act** on their ideas.
- **Engage** parents in the development of new ideas, program changes or improvements.
- **Keep asking, listening and engaging!**

Parent Partner

- **Passionate about hearing loss.**
- **Willing to share her experience and story with others.**
- **Advocates for others.**
- **Past EHDI Advisory Co-chair.**
- **Member of State QI Team.**
- **Member of NC Newborn Screening Program Fact Sheet Development Team.**



Photo credit: C&Y Branch

Jodi's Idea!

Create a prenatal education tool about newborn hearing screening so that prior to the birth admission, families would know about the in-patient hearing screening process and the importance of prompt additional testing if their infant did not pass the initial screening.



NC EHDI State QI Team Observations

- NC DPH has brochures on the individual screenings (metabolic screening, hearing screening).
- Minimal dissemination of these education materials during the prenatal period.
- Families tell us that they did not know that their baby was going to have a hearing screening.
- Congenital heart defects screening was added.
- Parents need to know about screenings **BEFORE** the birth admission so that they know what to expect.
- Parents need a list of resources so they can learn more about the different screenings and what the results may mean. Empower the parents.

WHY This Document?

- Jodi's idea + EHDI State QI team observations
- In collaboration with the State QI team, it was decided that the prenatal tool would encompass all NC newborn screenings including metabolic and congenital heart defect.



Ta-Da.... The Reveal

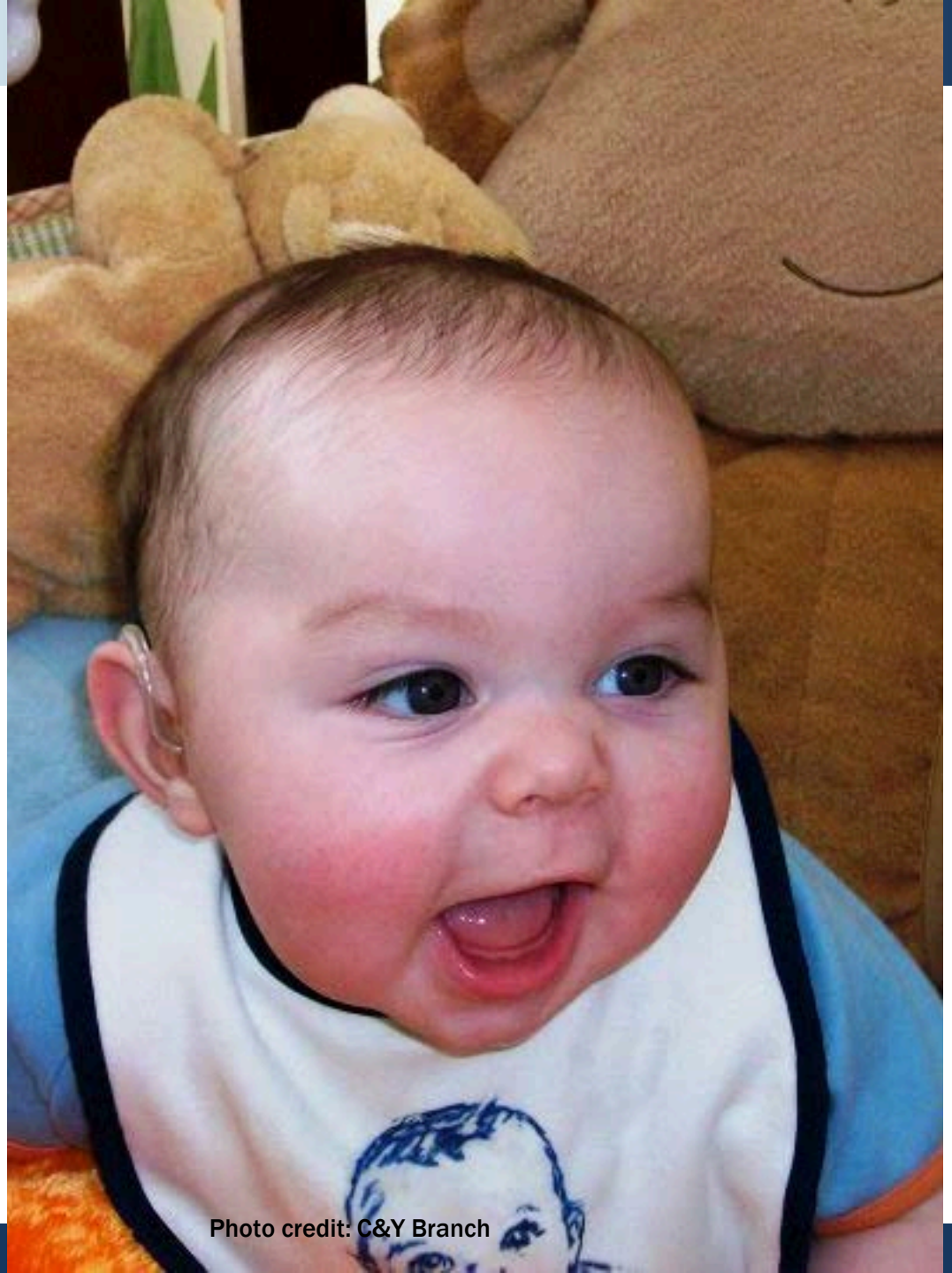


Photo credit: C&Y Branch

North Carolina's Newborn Screening Program



Most newborns are born healthy. However, there are some health problems that may not be found on a routine exam by your baby's doctor. Newborn screening tests are done to see if your baby might have a problem. We do not know for sure until more tests are done.

During your hospital stay, your newborn will receive three screening tests to check for serious health problems that may not be known at birth. The earlier a problem is found the better chance your baby will have for a healthier start in life.



**Blood Spot
(Metabolic) Screening**

Checks for over 35 possible serious health problems.

A few drops of blood are taken from your baby's heel and sent to North Carolina's State Laboratory of Public Health.



Heart Screening

Checks for serious life-threatening heart problems known as critical congenital heart defects (CCHD).

A small sticker will be placed on your baby's right hand and on your baby's foot to measure the amount of oxygen in your baby's blood.



Hearing Screening

Checks for hearing loss.

A special machine looks at your baby's response to sound. The screening needs to happen when the baby is sleeping or very quiet.

Your baby's results.

The blood spot (metabolic) screening takes a few days. Ask your baby's doctor for the results.

Your baby's hearing and heart screening results will be available before your baby leaves the hospital. Ask for your baby's results before you are discharged.

If your doctor asks you to come back for more testing, it is important to do so right away. Follow up quickly.

For More Information:

Contact the Children and Youth with Special Health Care Needs Help Line
Call: 1-800-737-3028

Email: CYSHCN.Helpline@dhhs.nc.gov

Your Baby's First Tests
babysfirsttest.org/newborn-screening/before-birth

 NC Screened Conditions and Disorders
slph.ncpublichealth.com/newborn

  NC Newborn Screening Services
ncdhhs.gov/dph/wch/families/newbornmetabolic.htm

 NC Newborn Hearing Screening Program
ncnewbornhearing.org



*This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H61MC00043, Universal Newborn Hearing Screenings. The total grant amount is \$250,000 and zero percent is financed with nongovernmental sources. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

N.C. Department of Health & Human Services, Division of Public Health www.ncdhhs.gov www.ncdhhs.gov/divisions/dph
DHHS is an equal opportunity employer and provider (02/2017)

How We Did It: Steps to Completion

1. Assembled a Collaborative Team

Parent Partner

Jodi Keegan

NC Division of Public Health (DPH), C&Y Branch

Jude Williams, MPH, EHDI Project Coordinator

Holly Shoun, MAT, EHDI Parent Consultant

Linda Bowen, M.S., CCC-SLP, EHDI Regional Consultant

Marcia Fort, Au.D, CCC-A, Genetics and Newborn Screening Unit Manager and EHDI Coordinator

Lara Percenti, MS, CGC, NC Newborn Screening Follow-up Coordinator

Kristin Dodge, MPH, Public Health Educator

NC State Laboratory of Public Health

Ann Grush, Newborn Screening Laboratory Improvement Consultant

NC DPH, Women's Health Branch

Belinda Pettiford, MPH, Women's Health Branch Head

How We Did It: Steps To Completion

2. Researched other states' prenatal fact sheets.
3. Developed a template.
4. Engaged a new mother and a pregnant woman in the review of the fact sheet and incorporated their suggestions.

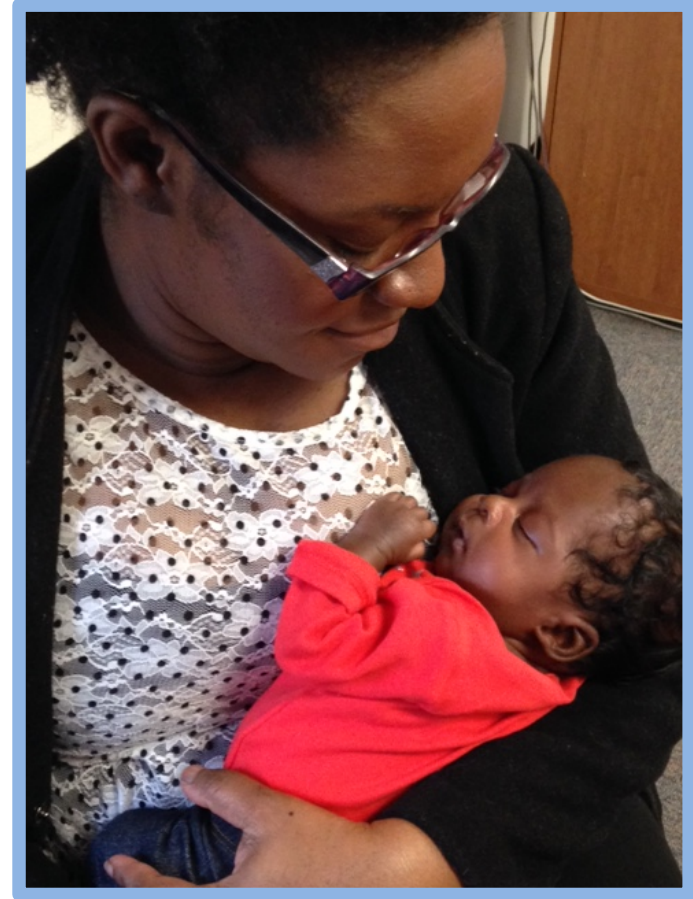


Photo credit: C&Y Branch

Assembly Required

Features of Accessible Print Material

- Message
- Visual
- Layout and Design
- Readability

Simply Put, A Guide for Creating Easy-to-Understand Materials. (2010, July). Retrieved from https://www.cdc.gov/healthliteracy/pdf/simply_put.pdf

Message

- **Keep it short and simple.**
- **Limit jargon, use clear and consistent language, avoid acronyms and abbreviations.**
- **Emphasize what audience SHOULD DO, not what they should not.**
- **Use active voice, when possible (Ask. Follow up quickly).**

Visual

- Easy to understand and close to corresponding text – help to explain the text.
- Use photographs to show real life events.
- Images should be representative and sensitive of the target audience.



Layout and Design

- Use 12 - 14 point font.
- Heading should be at least 2 points larger than text.
- Visually attractive.
- Use headings and subheadings or columns to break up text.
- Leave plenty of white space.

Readability

- **Materials should be written at 4th or 5th grade level.**
- **The NC Newborn Screening Program Fact Sheet tests at an 8th grade readability level. Repeated attempts were made to change the language but in doing so the needed message was diluted.**
- **Test materials with target audience.**

Other Requirements

- **Funding Agency**
- **Organization**

What's Next?



Photo credit: C&Y Branch

Translation

**Spanish is currently
underway.**

Dissemination

“I resolved to stop accumulating and begin the infinitely more serious and difficult task of wise distribution”.

-Andrew Carnegie, BrainyQuote.com

Where Did It Go?

- Hospitals, Health Departments, and PCP Offices
- Collaborated with Women's Health Branch – available on their website and order form
- EHDI Program Material Order Form
- Mailing to OB/GYN offices

Evaluation

- **Include survey re: usefulness in mailings and with order form. Include pre-paid postage envelope.**
- **On-line survey (obtain email address and send link to survey).**
- **Ongoing communication.**
- **Consider working with one office that is using the fact sheet, send survey to parents post delivery re: usefulness.**

Summary

“I’m not interested in competing with anyone. I hope we all make it.”

- Erica Cook

https://www.goodreads.com/author/show/7918404.Erica_Cook

**Thank
You!**

Questions?



Photo credit: C&Y Branch