Informing Parents About Newborn Screening: Hidden Problems, Practical Solutions

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Quality: Top health care issue
21st century

Newborn Screening Communication

- knowledge-based
- patient-centered
- systems minded

*IOM Quality Chasm: 2001
NBS Communication Stages

Initial Screening → Retest → Confirmed Positive

Parent informational & psychological needs vary
NBS Parent Education Background

- NBS parent education materials available in 49 of 51 states - mostly given in hospital
- No national guidelines for content or dissemination
- AAP-NBS Task Force recommends families be educated during the prenatal/ perinatal periods
- Prenatal NBS education is rare (class has limits)
- Pediatricians rarely discuss initial screening with parents
NBS Communication Challenges

✓ New technology/rapidly changing environment
✓ State programs differ (disorders screened, info given, process of reporting results)
✓ Parents/public lack basic knowledge
✓ Hospital birth visit a “fog” for most parents
✓ Primary providers may lack up-to-date information, patient education materials, time
✓ Best practices yet to be identified
Hidden Barriers to Informing Parents about NBS

Patients/ providers/nurses/ state programs:
✓ Agendas/ communication styles/ knowledge level differ

Patients:
✓ Education/ Literacy/ Language
✓ Health Literacy:
  *Capacity to*
  • Obtain, process, understand basic health information and services
  • Make appropriate health care decisions (act on information)
  • Access/ navigate healthcare system
Education in the U.S. today

School drop-out rates

- Russia: 2%
- Japan: 5%
- U.S.A. (16th): 29%
- U.S. cities: 35-45%
- U.S. black students: 50%

14% 9th graders finish college in 6 years

Job requirements in U.S.

- 20% 4 year college
- 65% Assoc. degree
- 15% minimum skills

½ of h.s. students can eventually get a job that supports a family
Health communication

Hot national topic

IOM: 2004 Report

- 90 million adults have trouble understanding and acting on health information
- Complex text must be simplified and attention paid to culture and language

Healthy People 2010

- Improve health communication/health literacy

JCAHO (1993); Balanced Budget Act (1997)

- Patients must be given info they can understand
National Adult Literacy Survey

n = 26,000

- Most accurate portrait of literacy in U.S.
- Scored on 5 levels
- Levels 1 and 2 cannot:
  - Use a bus schedule or bar graph
  - Explain the difference in two types of employee benefits
  - Write a simple letter explaining an error on a bill
1993 National Adult Literacy Survey

- Level 3: 32%
- Level 2: 27%
- Level 1: 21%
- Level 4: 17%
- Level 5 - 3%

High School grads

Atlanta: 38%
Baltimore: 38%
Chicago: 37%
Los Angeles: 37%
New York: 36%
Who’s at Level 1 nationally?*

Medicare recipients 42%
Medicaid recipients 41%
(over 1/3 births)

Low literacy LINKED to:†

• poor health
• lower quality care
• medical errors
• poor outcomes
• disparities

* NALS, 1993 † AHRQ Evidence Report 2004
Low Literate Diabetic Patients Less Likely to Know Correct Management*

Need to Know: symptoms of low blood sugar (hypoglycemia)

Need to Do: correct action for hypoglycemic symptoms

*Williams et al., Archive of Internal Medicine, 1998
Video

- 90 million Americans have trouble understanding and acting on health information
- Health information is often complex & unfamiliar to people of all education levels
- It’s easy to make a mistake
Mismatched Communication

**Provider Process/ State NBS Program:** Giving information

**Patient Process:** Understanding, remembering, and acting on information
Patient Education: What We Know

 ✓ Written materials, when used alone, will not adequately inform
 ✓ Simplified materials are necessary but will not solve communication problems
 ✓ Focus needs to be on “need-to-know” and “need-to do”
 ✓ Work with patients to identify best practices

* IOM: Report on Health Literacy 2004
* AHRQ Report 2004
Vaccine Communication Materials

7 Questions parents need to ask about baby shots:

1. What shots will my child get this visit?
2. Why should my child get these shots?
3. Is there any reason I should not give my child these shots?
4. What side effects could my child have?
5. What should I do if my child has a side effect?
6. What should I do if my child has a severe side effect?
7. When is my child's next shot?

T Davis. Ambul Peds; Fredrickson, Davis. Pt Ed Counsel
Vaccine Communication
Pre and Post Materials

T Davis et al, *Ambulatory Pediatrics, 2002*
HRSA Contract

✓ Evaluate user-friendliness, including readability and cultural appropriateness, of NBS parent education materials in English and Spanish (49 programs)

✓ Conduct listening groups of key stakeholders

✓ Develop pamphlets in English & Spanish for parents

✓ Work with NNSGRC to develop and evaluate educational tools for prenatal providers & toolkits for state programs

Gold Standard Readability: \( \leq 6^{th} \) Grade
Do Current Materials Work?

Readability is the tip of the iceberg.
**Is the layout user-friendly?**

1. **Is the layout user-friendly?**
   
   First impressions are important!
   
   Does the pamphlet:
   
   - Have ample white space?
   
   - Limit paragraphs to 4 to 5 lines?
   
   - Use bullets, boxes, indentation, bolding, vertical lists?
   
   - Use bifold rather than trifold format?
   
   - Use font that is 12 point or larger?
   
   - Avoid use of ALL CAPS, italics and specially fonts in large blocks of text?

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**Why does my baby need Newborn Screening tests?**

Most babies are healthy when they are born.

We test all babies because a few babies look healthy but have a rare health problem.

If we find problems early, we can help prevent serious problems like mental retardation or death.

**How will my baby be tested?**

Before you leave the hospital, a nurse will take a few drops of blood from your baby’s heel.

The hospital will send the blood sample to a newborn screening lab.

**How will I get the results of the tests?**

Parents are notified of test results if there is a problem.

Ask about results when you see your baby’s doctor.
2. Do illustrations convey the message?

A picture may be worth a thousand words – but which thousand?

Are pictures and captions:

• Serving a purpose (they are not just decorative)?
• Clear and realistic?
• Familiar and likely to be understood?
Is the message clear?

3. Is the message clear?
- Is the message obvious on the cover, title, and headings?
- Are key messages easy to pick out?
- Does pamphlet get to the point quickly?
- Does pamphlet easily inform the readers of what they need to know and do?

Does cover graphic:
- Target expectant parents?

These Tests Could Save Your Baby’s Life
Newborn Screening Tests
Is the information manageable?

Does the pamphlet:

- Focus on "need to know" rather than "nice to know"?
- Stick to a few key messages to avoid information overload?
- Limit the use of graphs and statistics?

Why does my baby need to be screened?

Routine newborn screening can determine if your baby has any of the following conditions: PKU (Phenylketonuria), Hypothyroidism, Galactosemia, Sickle Cell Disease or CAH (Congenital Adrenal Hyperplasia). These are rare, but serious conditions which can cause brain damage or even death if not treated. Even if your baby looks healthy, he or she may have one of these conditions. If any of these conditions go untreated, serious problems will arise. Therefore, state law requires that all newborn babies be tested. The blood tests will identify babies who need more testing, counseling and treatment. It is critical to detect these conditions as soon as possible. A few days or weeks could make the difference between life and death or disability.

(College Reading Level)

Why does my baby need Newborn Screening tests?

- Most babies are healthy when they are born.
- A few babies look healthy but have a rare health problem.
- Babies who are born with these diseases seem normal at birth.
- We test all babies to find the ones who may need treatment.
- If we find problems early, we can help prevent serious problems like mental retardation or death.

(7th Grade Reading Level)
Newborn Screening is offered to families with new babies as a service through the Department of Health. The initial screening tests are performed by the Department of General Services, Division of Consolidated Laboratory Services (DCLS) which is located in (city). DCLS also performs repeat tests on infants up to six months of age. This service makes it possible to find out whether newborn babies might have disorders that may result in serious problems if treatment is not started soon after birth. Every infant in (state) is tested a few days after birth unless a parent or guardian objects on the grounds that the test conflicts with their religious practices.

How will my baby be tested?

* Before you leave the hospital, a nurse will take a few drops of blood from your baby's heel.

* The hospital will send the blood sample to a newborn screening lab.
Avoid a Common Mistake

Most patient education materials sequence information using:

**Medical model**
- Description of problem
- Statistics on incidence and prevalence (tables)
- Treatment forms and efficacy

Is more helpful to use:

**Newspaper model**
- Gives most important information first

**Health belief model**
- Your baby may be at risk
- There is something you can do about it
- Your baby will get personal benefits if you do
Focus Group Research

22 focus groups & 3 interviews:

- English- & Spanish-speaking parents of babies recently screened
- Parents of babies who had a false positive
- Pediatric & prenatal care providers
- State newborn screening professionals

6 states  n= 138
### Parent Demographics

*(n = 51)*

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<tr>
<th>Ethnicity/Race</th>
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<th>Insurance</th>
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<tr>
<td>Black</td>
<td>22 (43%)</td>
<td>Private</td>
<td>23 (45%)</td>
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<tr>
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<td>Medicaid</td>
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<td>No Insurance</td>
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<tr>
<th>Sex</th>
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<tr>
<td>Female</td>
<td>48 (94%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (6%)</td>
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<table>
<thead>
<tr>
<th>Age of Child</th>
<th>6 wks- 1 yr</th>
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| Age of Parent      | 16-39          |                    |
## Provider Demographics

(n = 78)

<table>
<thead>
<tr>
<th>Health Profession</th>
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<tr>
<td>Family Physician</td>
<td>24 (31%)</td>
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<tr>
<td>Neonatologist</td>
<td>2 (3%)</td>
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<tr>
<td>Pediatrician</td>
<td>17 (22%)</td>
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<tr>
<td>OB/GYN</td>
<td>11 (14%)</td>
</tr>
<tr>
<td>Nurse Midwife</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>Labor and Delivery Nurse</td>
<td>11 (14%)</td>
</tr>
<tr>
<td>Physician Assistant</td>
<td>5 (6%)</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>4 (5%)</td>
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</tbody>
</table>

<table>
<thead>
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</thead>
<tbody>
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<td>White</td>
<td>64 (82%)</td>
</tr>
<tr>
<td>Black</td>
<td>9 (11%)</td>
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<tr>
<td>Hispanic</td>
<td>3 (4%)</td>
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<tr>
<td>Asian</td>
<td>2 (3%)</td>
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<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>43 (55%)</td>
</tr>
<tr>
<td>Male</td>
<td>35 (45%)</td>
</tr>
</tbody>
</table>

| Ages                         | 23-72 (range) |
Lessons Learned from Focus Groups

- Parents and providers had limited knowledge/ awareness of newborn screening- “not on the radar screen”
- Parents not familiar with term newborn screening
- Physicians did not know what NBS information parents were given in the hospital, none had read state brochure
- All stakeholders felt parents should 1st receive education prenatally “The hospital visit was a fog; the only thing I wanted to know was ‘is the baby ok?’”
- Physician and nurse education before discharge focused on practical things e.g. breast feeding, crying, car seats
Lessons Learned from Focus Groups

• Parents wanted ‘heads up’ about initial & retesting 7-8 months pregnant “This is the best time because I am going to the doctor almost every week.”

• Parents wanted information orally from their primary provider with a pamphlet to take home “I like to have a brochure because you don’t always remember everything your doctor tells you.”

• Pamphlet needs to be to the point, “I just want it as short and as simple as possible”

• Prenatal providers indicated willingness to educate parents

• OB’s and FP’s more likely to incorporate NBS information if it was on the ACOG checklist
Parent Experiences

• NBS pamphlets often given in hospital with no oral information; pamphlet often “lost” in take home package. "They give you so much information in the packet to take home with you, that you end up throwing most of it away.”

• Opinion mixed on “need to know” if result is negative. Most said, I don’t really care if everything is o.k. Others: I want to make sure my baby’s test did not fall through the cracks.

• Did not know state public health department was involved in testing and retesting. “I just kept trying to figure out how the health department got my name and knew I had just had a baby.”
List/ Description of Diseases

• Parents expressed little interest in detailed information on diseases or NBS program

• Parents did not read list of 32 diseases and descriptions; stopped reading when they realized they could not pronounce the word and had no basic knowledge of the disease, “I don’t want a lot of details.” “Put less information so people will read it. Make it more concise, less overwhelming.”

• Parents only interested in description of diseases when baby needed retest, then only in condition being tested “If my child has a test come back positive, I only want to know about that specific disease.”

• A few highly educated parents requested web links, and computer savvy moms turn to Google 1st when retesting is needed
“Need-to-know” Information for Parents

- All babies are screened
- Screening will **benefit** the baby
- Testing is **safe** - not harmful
- The baby may need to be **retested**
- Parents will be **notified if** retesting is needed
- It's important to **act quickly if retesting** is necessary

*Cost and consent were not important*
Why does my baby need Newborn Screening tests?
Most babies are just fine when they are born.
We test all babies because a few babies look healthy but have a rare health problem.
If we find problems early, we can help prevent serious problems like mental retardation or death.

How will my baby be tested?
Before you leave the hospital, a nurse will take a few drops of blood from your baby’s heel.
The hospital will send the blood sample to a newborn screening lab.

How will I get the results of the test?
Parents are notified of test results if there is a problem.
Ask about results when you see your baby’s doctor.

Why do some babies need to be retested?
All babies who leave the hospital early must be retested.
Some states require a second test on all babies.
Some babies need to be retested because there is a problem with the blood sample.
A few babies need to be retested because the first test showed a possible health problem.

What if my baby needs to be retested?
Your baby’s doctor or the State Health Department will contact you if your baby needs to be retested. They will tell you why the baby needs to be retested and what to do next.
If your baby needs to be retested, get it done right away.
Make sure that your hospital and doctor have your correct address and phone number.

What if I have questions?
Ask your baby’s doctor if you have questions or concerns.

Parents more likely to keep high quality materials and throw away copied handouts
To be produced & distributed by AAP. Will be available as an electronic template for states to use or modify
• Spanish speaking mothers want pamphlets in English & Spanish “I want to make sure I get all the information.” “I need one in Spanish to show to my family.”

18% of U.S. households do not speak English at home. (2000 census)
Lessons Learned from Providers

- Not interested in time- or resource-intensive training programs
- Preferred short handouts, checklists, brief articles in their professional organizations newsletters.
- Wanted to-the-point information to help them educate parents more effectively.

Providers requested brief information in a handy notebook to prepare them for conversations with parents:
- a list with concise definitions of the diseases screened
- the specific diseases screened for in their state
- sources of additional information
Challenges in Teaching/Reaching Physicians

- CME for NBS is not a *carrot*
- Computers had limited use with most practicing physicians (Family Physicians training residents more likely to use computers)
- Material mailed from professional organizations & the state health department would most likely get to be read by the physicians.
Recommendations

to improve quality of NBS communication

Information needs to be more patient AND provider centered
• Parents and providers need to be involved in development of materials and the distribution plan i.e. *what will be taught, when, where, how, by whom and how often.*

NBS needs to be more systems –minded
• Brief education at multiple times may be helpful *What is the role of office nurse, hospital staff?*
• Providers need to be more *in the loop*
• *Parent education needs to be convenient and practical for usual practice*
• Professional organizations, state agencies, HRSA and affiliated groups should collaborate more to prepare and motivate providers to educate parents
Provider Communication Tools
Brief Discussion Guide

7 Things Parents Want to Know About Newborn Screening:

THE HEALTH PROFESSIONAL’S GUIDE FOR BRIEF DISCUSSION WITH PARENTS.

1. All newborn babies are required by the State to get tested for some rare disorders before they leave the hospital.

2. Babies with these disorders may look healthy at birth.

3. Serious problems can be prevented if we find out about the disorders right away.

4. To do the test, a nurse will take a few drops of blood from your baby’s heel.

5. Your baby’s doctor and the hospital will get a copy of the test results. Ask about the results when you see your baby’s doctor.

6. Some babies will need to be retested. If your baby needs to be retested, you will be notified. It is very important to get retested quickly.

7. Talk to your baby’s doctor if you have questions. The Web site on the back of the brochure also has good information.
Brief Information to Facilitate Communication with Parents

**Louisiana Newborn Screening Information**

In Louisiana, the state mandates screening on all babies for 5 conditions.

- Phenylketonuria (PKU)
- Hypothyroidism (CH)
- Galactosemia (GAL)
- Biotinidase (BIO)
- Sickle Cell Diseases (SCD)

Beginning late 2004, the program will add a pilot test on all babies for five additional conditions. The additional tests will likely be mandated in the future.

- Homocystinuria (HCY)
- Maple Syrup Urine Disease (MSUD)
- Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
- Citrullinemia (CIT)
- Argininosuccinate Lyase Deficiency (ASA)

- All mandated screening is done at the Louisiana Department of Health Laboratory.
- Some hospitals use a private lab or their own lab to screen.
- There are other screening tests available outside of the mandated program, which parents may wish to investigate.
- Linkages to laboratories providing additional testing are available from the National Newborn Screening and Genetics Resource Center: [http://genescr.us.uflhcsa.edu](http://genescr.us.uflhcsa.edu)

The state NBS program can provide more information:

Phone: 504-568-5070

Website: [http://oph.dhh.state.la.us/geneticdisease/newbornscreen](http://oph.dhh.state.la.us/geneticdisease/newbornscreen)
Provider Notebook to Facilitate Prenatal Parent Education

Pilot to evaluate feasibility & satisfaction

- Materials were mailed to 25 providers in 4 states (GA, LA, NM, TX) 32% FP; 24% OB; 8% Midwives; 2% NP
- Providers used the materials for one month with a total of 240 English-speaking and 130 Spanish-speaking parents (48% Medicaid)
Results of Pilot Parent Education Project

• **92%** reported being highly satisfied with **all** of the materials

• **84%** found the “7 Things” helpful; **80%** were likely to use it on an ongoing basis

• **88%** thought the parent pamphlets were relevant prenatally; **80%** were likely to use them on an ongoing basis
Results of Pilot Project, contd.

- **100%** found the quick reference helpful and thought it contained the right amount of information for them.

- **92%** found state-specific screening information helpful; **only 12%** visited the **state website** listed.

- NBS education using the materials took **2-5 minutes**.
Toolkits for State NBS Programs

• **C.D. in “jewel” case:**
  - Electronic-templates of English and Spanish parent pamphlets that states can tailor to meet their needs
  - Electronic-pictures of parents and young babies

• **Printed guide to developing user-friendly NBS pamphlets**

  ![Image](image.png)

  **What's in the Patient Education Toolkit?**
  - Six things to consider in making patient materials user-friendly
  - Electronic templates of initial and retesting brochures in English and Spanish that can be tailored for your program
  - Tips for tailoring the sample brochures for your program
  - Collection of high resolution photographs of newborns and parents
  - A quick guide to designing patient education materials
  - A list of helpful resources/references

• To be distributed by the NNSGRC
NBS Education Ideal

✓ Parent-centered materials/messages delivered 1st prenatally
✓ Messages given multiple times
✓ OB and pediatric providers more involved in the system
✓ Provider centered “need to know”/ “need to do” education
✓ Public awareness campaign may be needed
✓ Quality control to ensure consistency and efficacy of education