

Survey of States for Policies and Procedures for Public and Professional Education

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Newborn Screening Task Force Report

- ◆ Vol. 106, Aug. 2000, Suppl.
- ◆ Approved by:
 - AAP Board of Directors
 - AAP Committee on Genetics
 - AAP Committee on Fetus and Newborn
 - Medical Home Initiatives for Children with Special Needs-Project Advisory Committee
 - AAP Task Force on Newborn and Infant Hearing

PEDIATRICS

August 2000
Volume 106
Number 2
Part 2 of 3

American Academy of Pediatrics



S U P P L E M E N T T O P E D I A T R I C S

Serving the Family From Birth to the Medical Home

*A Report From the Newborn Screening Task Force
Convened in Washington DC, May 10–11, 1999*


Sponsoring Organizations:

*Health Resources and Services Administration
American Academy of Pediatrics*

Co-Sponsoring Organizations:

*Agency for Healthcare Research and Quality
Association of Maternal and Child Health Programs
Association of Public Health Laboratories
Association of State and Territorial Health Officials
Centers for Disease Control and Prevention
The Genetic Alliance
National Institutes of Health*

*Funded in part by a grant (6MCJ-17R003) from the Maternal and
Child Health Bureau, HRSA.*

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1. Newborn Screening
Professional Education
 2. Newborn Screening
Public/Parent Education

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1. Newborn Screening Professional Education

Newborn Screening Professional Education

AAP Taskforce Key Recommendations Regarding Professional Education

“States and state public health agencies should implement mechanisms to inform and involve health professionals and the public”

“Each state should: Design and implement public, professional, and parent education efforts regarding newborn screening”

Newborn Screening Professional Education

AAP Taskforce Key Recommendations Regarding Professional Education

“ Prenatal health care professionals as well as the infant’s primary care health professional should be knowledgeable about their state’s newborn screening program through educational efforts coordinated by the state’s newborn screening program in conjunction with a newborn screening advisory body”

Newborn Screening Professional Education

Education Tools and Resources for Health Professionals Responsible for Prenatal Care (i.e. obstetricians, family practice physicians)

- Although newborn screening advisory committees often include pediatricians and family practice physicians, they typically do not include obstetricians
- Only a few NBS programs (20%) provide brochures to obstetricians for distribution to their patients

Newborn Screening Professional Education

Education Tools and Resources for Health Professionals Responsible for Newborn Screening Specimen Collection

- Provider manuals
- Collection posters
- Newsletters
- NCCLS NBS collection video, or in-house video
- Formal on-site training
- Website

Newborn Screening Professional Education

Education Tools and Resources for Primary Care Providers Responsible for Follow-up of Presumptive Positive Screens

- Provider manuals
- Disorder fact sheets
- Follow-up act sheets or procedures
- Pediatric sub specialist contact information
- Website – (Online state information ranging from brief NBS program overviews (6 sites) to multilayered sites with detailed information on disorders, laws/regs, and resources (23 sites))

Newborn Screening Professional Education

Summary

- Although the prenatal period has been identified as the optimal time for parent education on newborn screening, prenatal providers are not receiving the necessary training to provide appropriate education to parents
- States are providing education and resources to birthing facilities, with a primary focus on specimen collection
- States typically provide “just in time” information to primary care providers. Primary health care providers rely on sub-specialists to educate parents of affected children in specifics of the condition

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2. Newborn Screening Public/Parent Education

Newborn Screening Public/Parent Education

AAP Task Force Key Recommendations On Public/Parent Education

“Parents should receive information (on behalf of their children) about newborn screening”

“Prospective parents should receive information about newborn screening during the prenatal period. Pregnant women should be made aware of the process and benefits of newborn screening and their right of refusal before testing, preferably during a routine third trimester prenatal care visit

Newborn Screening Public/Parent Education

Communication Practices Between State Newborn Screening Programs and the Medical Home

- Newborn screening roles and responsibilities vary between states and do not always include primary care physicians
- 23 states (45%) indicated that primary care physicians (i.e. the medical home) had some responsibility in informing parents about newborn screening
- 13 states (25%) reported that the state has a policy encouraging or requiring that parents be informed about newborn screening during the prenatal period
- 3 states were unable to report a procedure for informing parents about newborn screening

Newborn Screening Public/Parent Education

Current Status of Educational Activities

- 20 programs with requirements for states to provide specific information on newborn screening before screening takes place
- Educational items required included information on:
 - the right to refuse screening
 - the panel of disorders
 - the consequences of treatment and non-treatment
 - the need for retesting
 - retention of samples
 - confidentiality and privacy issues

Reference: Therrell B. , Johnson A. , Williams D., "The Current Status of Newborn Screening Programs in the United States" - In Press

Newborn Screening Public/Parent Education

Education Tools and Resources for Parents Prior to Testing

- Brochures (Available in all but 1 NBS program)
- Posters
- Videos
- Website (All programs have newborn screening information for parents online, ranging from basic program descriptions and contact information, to multilayered sites with FAQ's, disorder definitions, links to support groups and other resources)

Newborn Screening Public/Parent Education

Education Tools and Resources for Parents of a Child with a Confirmed Condition

- Disorder specific brochures
- Videos
- Newsletters
- Website (All programs have newborn screening information for all parents online, ranging from basic program descriptions and contact information, to multilayered sites with FAQ's, disorder definitions, links to support groups and other resources)

Newborn Screening Public/Parent Education

NNSGRC State Newborn Screening Parent Brochure Survey

- 23 questions focused on the information contained in the newborn screening brochure, and the mechanism for dissemination
- E-mailed survey to follow-up personnel in 50 states and D.C.
- Programs not responding to the e-mail were contacted by telephone so that all 51 programs participated
- All programs had a brochure (except 1) and graciously submitted a copy for further evaluation of literacy and cultural sensitivity

Newborn Screening Public/Parent Education

Brochure Survey Results - Distribution

1. 10 programs (20%) reported typical distribution by obstetricians
2. 14 programs (28%) reported typical distribution in prenatal classes
3. 19 programs (38%) reported having a mandate for distribution at birthing facilities

Newborn Screening Public/Parent Education

Brochure Survey Results - Content

1. All brochures included:
 - a list of screened conditions
 - information on time of collection
2. Most brochures included:
 - the collection procedure - 49 (98%)
 - a brief description of each condition - 47 (94%)
 - the potential need for retesting - 47 (94%)

Newborn Screening Public/Parent Education

Brochure Survey Results - Content

3. More than half of the brochures included:
 - how results could be obtained by parents - 36 (72%)
 - how results were reported to the PCP - 31 (62%)
 - citation of legal authority - 29 (58%)

4. Less than half of the brochures included:
 - possibility of false positive results - 24 (48%)
 - when results would be available - 20 (40%)
 - circumstances for refusal - 19 (38%)

Newborn Screening Public/Parent Education

Brochure Survey Results - Content

5. Brochures rarely included information on:

- accuracy of screening - 12 (24%)
- limitations of screening - 12 (24%)
- possibility of false negative results - 11 (22%)
- cost/payment for testing - 11 (22%)
- retention of specimens - 7 (14%)
- confidentiality and privacy issues - 4 (8%)

Newborn Screening Public/Parent Education

Summary

- The need for public/parent education is well understood by newborn screening programs, and all make an effort to provide printed and online materials and resources
- A brochure with basic program information is the main educational tool, however, it is generally not given at an optimal time
- Most programs lack an education plan that includes assessment and monitoring of material distribution, and an overall assessment of parent education efforts
- Obstetricians, who should have a responsibility for prenatal education, are generally not intimately involved with screening programs (e.g. advisory committees, etc.)