

A Consumer Perspective on Newborn Screening

The Advisory Committee on Heritable
Disorders and Genetic Diseases in
Newborns and Children

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The Information Age:

Models based on new economic constructs

Industrial Age (old)

Control means of production

Based on **scarcity**

Hierarchical / Command & Control

Linear / Sequential

Win / Lose

Material/Object

Information Age (new)

Open means of production

Based on **abundance**

Network / Collaboration

Organic/Dynamic

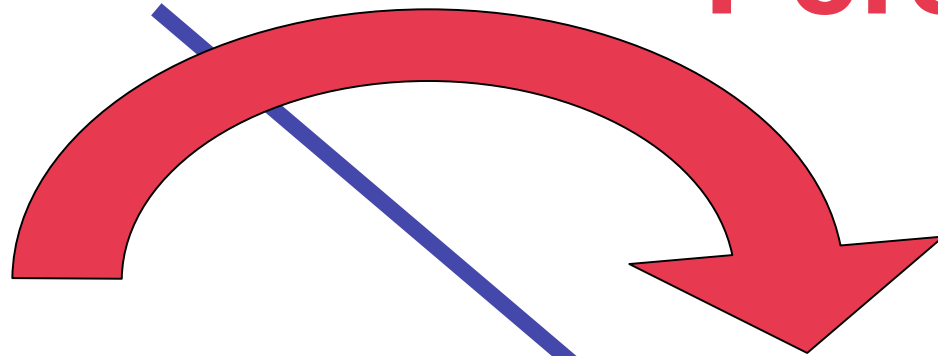
Win / Win

Information

Access to Services

- Accessible
- Integrated/coordinated - Medical Home
- Quality information - Evidence based
- No discrimination: services, insurance, employment, underserved communities

Perspective



Affected

(Advocates)

Unaffected

**(general
public)**

Appeals from Advocates of Newborn Screening

- Continuum from the universal panel to secondary panel to tests for all conditions
- Appreciate test benefits beyond the medical model (testing only for conditions with treatments)
- Full use of available technology

Concerns of general public

‘False Positives’

- Receiving a newborn screening result that indicates the newborn should be tested for a condition, and the subsequent test shows the newborn does not have the condition
- Risks of trauma to the family
- “Parents more overprotective and more focused on physical symptoms of their child when a false-positive result occurred.”

(Expanded Newborn Screening for Biochemical Disorders: The Effect of a false-Positive Result. Elizabeth A. Gurian, BSa, Daniel D. Kinnamon, MSb, Judith J. Henry, MSN, RNC and Susan E. Waisbren, PhD. PEDIATRICS. Vol. 117 No. 6 June 2006, pp. 1915-1921)

Concerns of general public

Carrier Identification

- Less exchange of information compared to carrier screening
- Parental anxiety, cost of follow up testing, stigmatization, misattributed paternity
- Informed decision making

Education

- Timing
- Knowledge of healthcare professionals
- Informed decision making

Consumer Focused Newborn Screening



Two cooperative agreements to determine consumer concerns and issues about:

- Education needed
- False positives
- Carriers



Consumer Focused Newborn Screening

- Engage Consumer Task Force on NBS
- Engage National Advisory Committee
- Spectrum of viewpoints on screening
- Educate other consumers to be active in NBS
- Change in perception of NBS issues
- Attention to the proceedings of this committee

Consumer Taskforce on Newborn Screening

Partnering Advocacy Organizations

- Cares Foundation
- Children's Sickle Cell Foundation
- Citizens for Quality Sickle Cell Care Foundation
- Hunter's Hope Foundation
- Save Babies through Screening Foundation

and

Parents who have experienced 'false positives', carrier identification and uneventful NBS



Consumer Focused Newborn Screening

University of Maryland School of Medicine

Impact of false positive screens and carrier
identification on:

- Newborn
- Family
- NBS system



Consumer Focused Newborn Screening

Qualitative • Year 1

Annotated bibliography

Unstructured interviews

Focus groups in three states

Develop data collection instruments and processes that will be used in the second year

Pilot the data collection instrument

Identify gaps in information by reviewing the existing NBS communication strategies

Initial phases of brainstorming possible models for improving NBS that would reduce harm



Consumer Focused Newborn Screening

Qualitative • Year 2

Interviews -

False positive screens or carrier identification

Control subjects who have experienced negative screens

Referrals for heart murmur that proved to be “innocent”

NBS Conference



Consumer Focused Newborn Screening

Qualitative • Year 3

Analysis and development of models to resolve identified problems in the screening process

Strategies for family-centered and medical home-based communication or system design that will minimize harm as well as further avenues of study to better understand potential economic harms resulting from false+ screens and carrier identification



Consumer Focused Newborn Screening

Genetics and Public Policy Center

Public's awareness of inherent issues in
newborn screening

- Availability
- Expansion
- Follow up

Increased parental education



Consumer Focused Newborn Screening

Quantitative • Year 1

Annotated bibliography

National Council of State Legislatures

Gap analysis

Survey development

Postulate consumer education models,
reassessment



Consumer Focused Newborn Screening

Quantitative • Year 2

Survey through Knowledge Networks Web-enabled
Panel - gives computers to diverse cohort

Men and Women, 18 - 44 yrs old

Half child within last two years

Half who plan to become pregnant

NBS Conference



Consumer Focused Newborn Screening

Quantitative • Year 3

Create models for intervention: for exchanging information with parents and addressing the public's awareness of NBS issues

Develop a one-page checklist for primary care providers at the time of any positive screen

Focus on using existing infrastructure to execute some of the recommended interventions

Submit papers for peer-reviewed publications, and presenting at national meetings

Iowa Family Participation Project

Focus on populations who usually do not participate in NBS, understanding the barriers, and looking at systems that could help include these populations.

- Year 1: healthcare providers including members of AAP and ACOG will be engaged to see how they and patients be included in the NBS system.
- Year 2: Information and Education Committee will convene to develop appropriate educational materials as well as a communication model.
- Year 3: Distributed materials will be evaluated.

NBS Financial, Ethical, Legal, and Social Issues

- Interviews regarding false positive results and key informants
- Collaboration with Western States
- RAND Corporation performing the evaluation.
- Include parents who have gone through a false positive screen as well as a control group.
- Parents (and future parents) of newborns will be surveyed to evaluate materials.