



# Newborn Screening and Health Care Reform

Presented to the Advisory Committee on  
Heritable Disorders in Newborns and  
Children, January 21, 2010

# Revisions based on comments from the Committee, HRSA staff and March of Dimes

## Recommendation 1

- September 2009  
Ensure stable funding for core and critical public health functions such as immunizations and screening
- Revised  
Convene an expert panel to establish a minimum recommended standard of service and care for each component of the newborn screening system—education, screening, diagnosis, follow-up/tracking and evaluation services

# Revisions based on comments from the Committee, HRSA staff and March of Dimes

## Recommendation 2 -- New

- Develop national guidance on creating public health budgets for newborn screening systems in order to minimize geographical disparities and highlight budget alternatives that may better serve the needs of a particular state program.

# Revisions based on comments from the Committee, HRSA staff and March of Dimes

## Recommendation 2 (new), continued

- The guidance should incorporate the flexibility in funding design that states may require and identify areas that the federal government may target for additional support to help states deliver the minimum standard of service and care set forth in recommendation 1.

# Revisions based on comments from the Committee, HRSA staff and March of Dimes

## Recommendation 3 (previously 2)

- Unchanged: Convene an expert panel to examine the billing and payment practices for the cost of screening services and to put forth recommendations that enhance the standardization of health care transactions

# Revisions based on comments from the Committee, HRSA staff and March of Dimes

## Recommendation 4 (previously 3)

- September 2009  
Work with the Centers for Medicare and Medicaid to develop and pilot a bundled payment method for providers treating the same child with a disorder diagnosed as a result of screening that can serve as a model for all children with special health care needs

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## Recommendation 4 (previously 3)

- Revised  
Work with the Centers for Medicare and Medicaid to pilot a payment method for providers treating the same child with a disorder diagnosed as a result of screening that incentivizes care coordination

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## Recommendation 5 and 6 (previously 4 and 5)

- Unchanged: Further define and adopt the meaningful use case for newborn screening for health information exchange endeavors by the Department
- Unchanged: Close gaps in insurance coverage for medical foods and foods modified to be low in protein as recommended by the Committee in April 2009



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## Electronic health records

- Language added in summary and text: Newborn screening is among the first encounters where health professionals begin to compile medical information about an individual and is thus a prime area for introducing electronic health records.

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## Additional comments

- Delete textual references that suggest all states should conform to a single design and financing methodology.
- Regarding recommendation 2, the paper does not build a case for an expert panel on billing and payment.

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## Additional comments

- Regarding recommendation 4 (now 5), it is a good idea that may need more discussion in the paper.
- Add a recommendation on the urgent need for educational materials and a full-on national campaign to educate parents and health professionals about the availability of and need for newborn screening.

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## Additional comments

- Regarding recommendation 5 (now 6), medical foods should be discussed further in the paper, and a proposal should be added to convene a working group that includes FDA, CMS and Tricare representatives to consider expanding federal support for public program coverage of medical foods.

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## Additional comments

- There was concern about creating an unfunded mandate for state programs. It was noted that recommending federal funding to support programs that are not addressing components of the newborn screening system might provide a disincentive for states that are already paying for these activities to no longer fund them if federal funding becomes available.

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## Additional comments

- A National Coverage Decision by CMS related to newborn screening might help to resolve some of the billing and payment issues.
- With regard to medical foods coverage, it was noted that shipping often constitutes a significant portion of patient costs.

# Contact Information

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