



Newborn Screening and Health Care Reform

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Newborn Screening and Health Care Reform: General Themes

- As with health care system overall, there is unequal access to newborn screening (NBS) services across the country
- The reasons behind disparities in NBS mirror problems with the broader health system:
 - Public financing
 - Payment systems
 - Administrative inefficiencies
 - Insurance coverage issues

Public Financing

Features of Current NBS System

- Combination on funding streams from fees, Maternal and Child Health Title V Block Grant funds, state appropriations and general revenues
- Existing support only provides for some education efforts, screening, diagnosis, and initial confirmation of treatment in half of the states
- Fees do not correlate with number of mandated tests

Public Financing

Recommended Reforms

- Ensure stable funding for core and critical public health functions such as immunizations and screening
- (Note: Developing national guidance for developing public health budgets suggested in paper but not listed as a recommendation)

Payment systems

Features of Current NBS System

- Billing and payment practices vary from state to state
- Lack of financial incentive to coordinate care

Payment systems

Recommended Reforms

- 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

Payment systems

Recommended Reforms

- 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

Administrative Inefficiencies

Features of Current NBS System

- Lack of funding to support e-health activities for state public health departments
- Efforts to promote electronic exchange of NBS information (ONC, NICHD)



Administrative Inefficiencies

Recommended Reforms

- Further define and adopt the meaningful use case for newborn screening for health information exchange endeavors by the Department

Insurance Coverage Issues

Features of Current NBS System

- State policies that require insurance coverage for medical foods vary and are not comprehensive
- Gaps in coverage of necessary medical foods and foods modified to be low in protein result in financial burden for some families

Insurance Coverage Issues

Recommended Reforms

- 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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