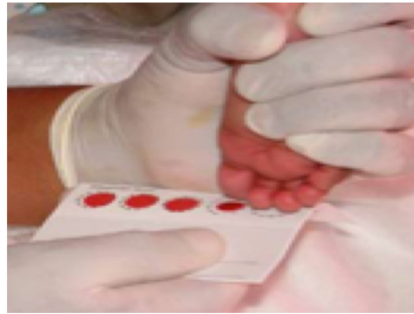
Impact of the Affordable Care Act's Coverage Mandate on State Newborn Screening Programs



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Disclaimer

This presentation was prepared under contract with the Department of Health and Human Services (HHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE). The findings and conclusions presented are those of the author and do not necessarily represent the views of ASPE or HHS.

Methods

- Exhaustive review of relevant literature, resource websites, state law
- Consultations with federal experts at HRSA and CDC
- Specific inquiries and conversations with state program leaders

ACA-mandated coverage without cost-sharing: 31 core + 26 secondary conditions

- 20 metabolic disorders (ex.: phenylketonuria)
- 2 endocrine disorders (ex.: primary congenital hypothyroidism)
- 3 hemoglobin disorders (ex.: sickle cell anemia)
- 6 others, including critical congenital heart disease, severe combined immunodeficiencies, and hearing loss
- 1 lysosomal storage disorder (3/2015 approval)

States’ adoption of RUSP

- Programs are 50+ years old and very diverse
- Typically reviewed and recommended by states’ versions of RUSP advisory group
- Full implementation often contingent on funding availability, particularly for new instrumentation and training that must be paid for before the first billable screening can be conducted
- Occasionally in statute

States' adoption of RUSP

- Only 5 states have fully implemented all 31 core RUSP tests
- 26 states have full SCID implementation as of April 2015 and the number grows rapidly
- Hearing and CCHD are the others most commonly missing from full state panels
- As point-of-care tests, hearing and CCHD may be billed differently

Payment models

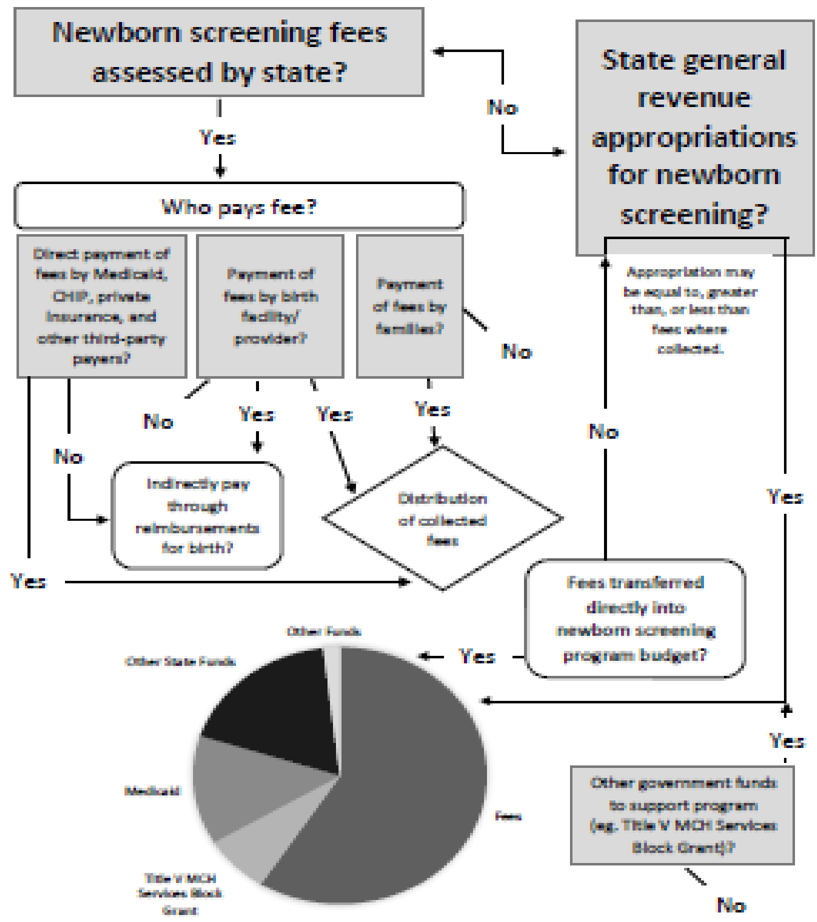
- Most common: birthing facility prepays state agency for heelstick test kits and includes the cost in newborn care charge along with CCHD and hearing
- Also common: birthing facility gets test kits at no charge and pays state agency at the time kits are submitted, the includes cost in newborn care charge along with CCHD and hearing
- Less common: state agency bills some payers but not all; some states have specific arrangements with Medicaid because of delays in identifying billing numbers etc.
- 3 states and DC have no state fee, but in PA only 6 tests covered; others are billed

Payment issues

- Smaller facilities may contract with independent hearing test vendor that bills third-party payers or families directly
- Parents may not be aware that they are entitled to coverage without cost-sharing
- ACA mandate only covers screenings, not full program costs
- Access to full RUSP may be complicated in the states that have not yet implemented it

Funding sources

- Fees collected from health care providers, who pass them on to third-party payers and in some cases, to parents (90% of respondents)
- Federal pass-through sources including Title V block grant and HRSA funding (61% of respondents)
- State general fund appropriations (33% of respondents)
- Direct Medicaid payments beyond routine newborn care (24% of respondents)



Source: Johnson K, Lloyd-Puryear MA, Mann MY, Ramos LR, Therrell BL. Financing state NBS programs: sources and uses of funds. *Pediatrics*. 2006; 117(5): S270-S279.

Fund flows (from 2006 survey)

Related issues

- State systems are typically fragmented: hearing screenings are administered separately and there no unified report on a single newborn
- High false positive rate requiring much follow-up testing
- Tendency for children in socially disadvantaged households to have lower follow-up rate

Comments from interviewees

- States are probably not realizing all the fee revenue to which they are entitled because of limited agency capacity for third-party billing
- Medicaid identification numbers can take months to materialize, leading to delays and lapses in payment
- Families that receive separate bills for hearing testing may not know whether they are eligible for full coverage—how to get the word out?
- Beware of unintended consequences from ACA coverage limitation to screening alone

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