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

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Disclaimer

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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

Question 1: States' adoption of RUSP

- Additions to state mandates 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

More on states' adoption of RUSP

- Few states have fully implemented all 31 core RUSP tests (see NewSteps website)
- 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

Question 2: 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

Issues with both of these models:

  - Is the amount of the fee adequate to support the full program?
  - Does fee revenue stay in the agency incurring the cost of testing, or does revenue go to the state general fund (requiring reallocation) or an NBS-specific fund within the general fund?

More payment models

- 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
  - These states use a combination of general fund and Title V support

Payment issues

- Repeat testing coverage is highly variable
- 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

Question 3: Funding sources

- Fees collected from birthing facilities, who pass them on to third-party payers and in some cases, to parents (90% of respondents)
  - Reportedly difficult to get fee increases in some states
  - May have to recompete for fee revenue from general fund
- Federal pass-through sources including Title V block grant and HRSA funding (61% of respondents)
- State general fund appropriations (33% of respondents)
  - Appropriated funds may originate with NBS fees
- 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.

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 (an argument for facility-based 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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