

Improving Newborn Screening Processes

Every year, millions of newborns are routinely screened for genetic and metabolic conditions as part of the newborn screening (NBS) process. Though these conditions are rare, if identified and treated promptly, newborn health outcomes can improve and potential disabilities can be avoided or mitigated. NBS has improved or saved the lives of more than 12,000 newborns each year. NBS programs are carried out at the state level and a majority screen for at least 29 of the 31 [conditions](#) recommended by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children.

On the whole, states perform well on the Maternal and Child Health Bureau's Title V national performance measure of the "percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their state-sponsored newborn screening programs." However, a November 2013 [report](#) in the *Milwaukee Journal Sentinel* found evidence of serious delays in newborn screening programs across the country. The paper requested NBS data from every state and the District of Columbia. Thirty-one states provided data; the paper analyzed the data, and then made it searchable for the public. According to the report, in 2012, at least 160,000 blood samples from newborns arrived late to laboratories for testing because: many labs are closed on weekends and holidays, hospitals do not send the samples via overnight delivery or courier services, and there are no consequences to hospitals that send late samples. Information about hospital performance is not typically made public, making it difficult to have a transparent process.

State Initiatives to Improve Newborn Screening Programs

- **Arizona Department of Health Services** developed its [Transit Time Project](#) to track progress toward its goal of receiving 95 percent of all first screen samples within 72 hours of collection. The department also added laboratory coverage on three-day holiday weekends and has begun contracting with an in-state courier for Saturday deliveries and pickups, with the potential for expanded services for all NBS samples.
- **Connecticut** is considering a [bill](#) that mandates a timeframe on the screening process, from submission to reporting. The proposed legislation would require that all newborn blood specimens submitted to the public health laboratory are tested and that the results of the screening are reported to the infant's primary care provider within 24 hours of submission.
- Lawmakers in **Missouri** are considering a new budget plan which would provide an additional \$150,000 for state public health laboratories to be open on Saturdays and to expand courier services on Sundays.
- **Texas** is tracking and improving blood sample transit times. The Texas Department of State Health Services expanded courier pickups to weekends and holidays and is exploring the potential to work with a commercial overnight carrier to deliver NBS specimens only.
- In March 2014, **Washington State** passed a [bill](#) that requires timely collection, submission, and receipt of NBS samples; requires hospital report of notification; and requires published reports from the health department.
- In January 2014, **Wisconsin Newborn Screening Program** developed a mechanism to report back to hospitals critical performance metrics, including how long it took for babies' blood samples to arrive at the state lab. Hospitals will also work with courier services to add Saturday pickups at more facilities.