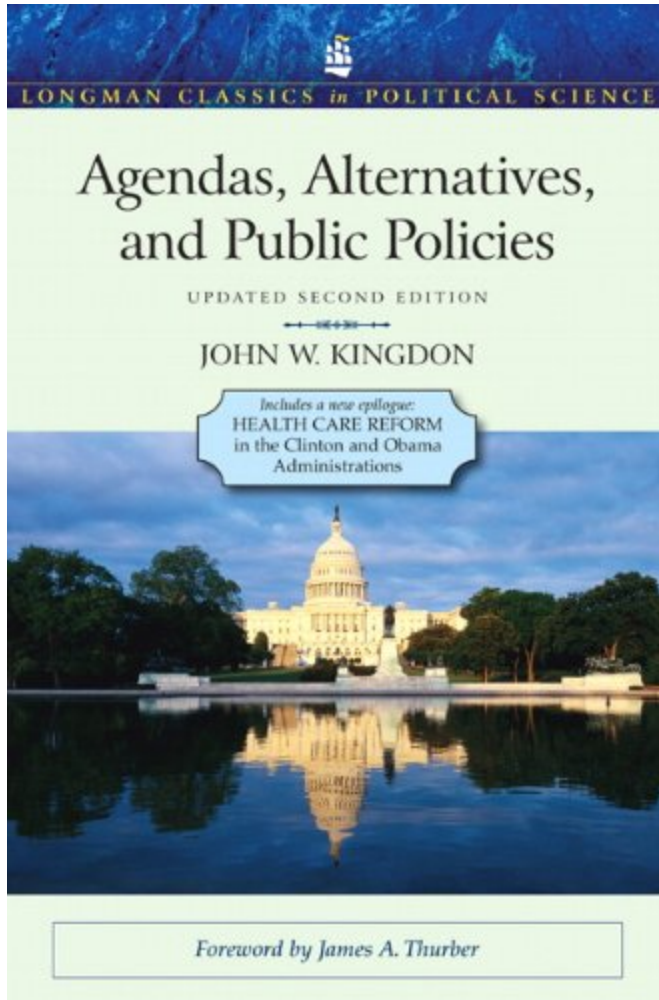




Recognizing Windows of Opportunity: Washington State's Response to the Milwaukee Journal Sentinel

John D. Thompson, Mike Glass, Santosh Shaunak,
Sheila Weiss and Lain Knowles
Washington State Department of Health,
Newborn Screening Program



“Once the window opens, it does not stay open for long. An idea’s time comes, but it also passes... [And] if the window passes without action, it may not open again for a long time.”

- John W. Kingdon

WA NBS coverage

- Washington State NBS law written in 1977
 - Required NBS for hospital births by age 5d
- Active midwife participation – not required
- No traction to make changes

- 2008 – MSUD case – still no traction to change law

- 2011 – CF case

Deadly Delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.



Kristyna Wentz-Graff/Journal Sentinel

Delays at hospitals across the country undermine newborn screening programs, putting babies at risk of disability and death



The
Seattle
Times

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November 19, 2013 at 4:35 PM

Some local hospitals not quickly screening all newborns

Posted by [Gene Balk](#)

Unless you're a parent or medical professional, you may not know that all newborn babies in Washington and across the country have their blood screened to detect rare diseases.

The timing of blood screenings is critically important because newborns afflicted with certain rare disorders can fall sick within just a few days of leaving the hospital. Early detection through these screenings saves 12,000 babies each year in the United States from death or irreversible harm.

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Swedish Medical Center on First Hill (Photo: Joe Mabel/Wikimedia Commons)

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Spokane County hospitals were worst in state for sending newborn blood samples on time

John Stucke [The Spokesman-Review](#)

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[Newborn screening questions for parents to ask of hospitals](#) November 24, 2013

Two hospitals in Spokane County had the worst record last year in Washington for sending newborn screening samples on time to the state's specialized lab.

At Valley Hospital, more than 28 percent of all newborn blood samples – 288 in all – arrived at the lab later than the five days mandated by state law. And at Deaconess Hospital, almost 18 percent of samples – 478 in all – arrived

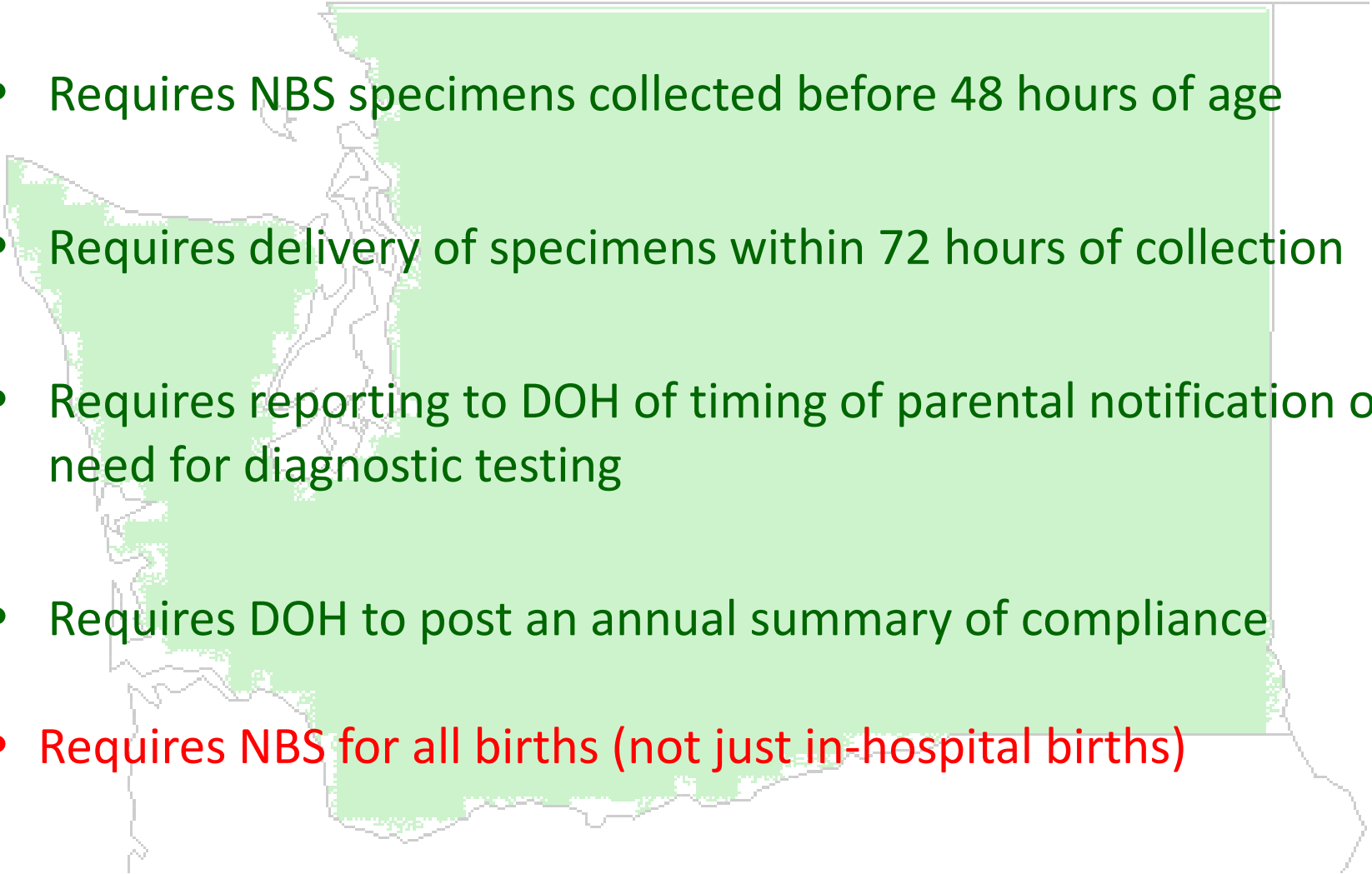
late to the lab.





Amended NBS Law

- Requires NBS specimens collected before 48 hours of age
- Requires delivery of specimens within 72 hours of collection
- Requires reporting to DOH of timing of parental notification of need for diagnostic testing
- Requires DOH to post an annual summary of compliance
- Requires NBS for all births (not just in-hospital births)





Midwife billing

Changes to reporting

New collection cards

PCP reporting

Annual compliance report

Apple Carts

- Recognized the Window of opportunity
 - Carefully timed request aimed at tightening the NBS safety net to cover all births not just hospital births
- Overall
 - much bigger implications than we expected
 - and a very positive experience





Washington State Department of
Health