

# Screening for Critical Congenital Heart Disease Using Pulse Oximetry

**Jill Glidewell, APRN, MSN, MPH**

Epidemic Intelligence Service Officer

National Center on Birth Defects and Developmental Disabilities

Association of Maternal & Child Health Programs Webinar

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# Outline

- ❑ **Federal role in implementation of CCHD Screening**
- ❑ **State activities with CCHD Screening**
- ❑ **Survey of birth defects surveillance programs**



# Federal Activities

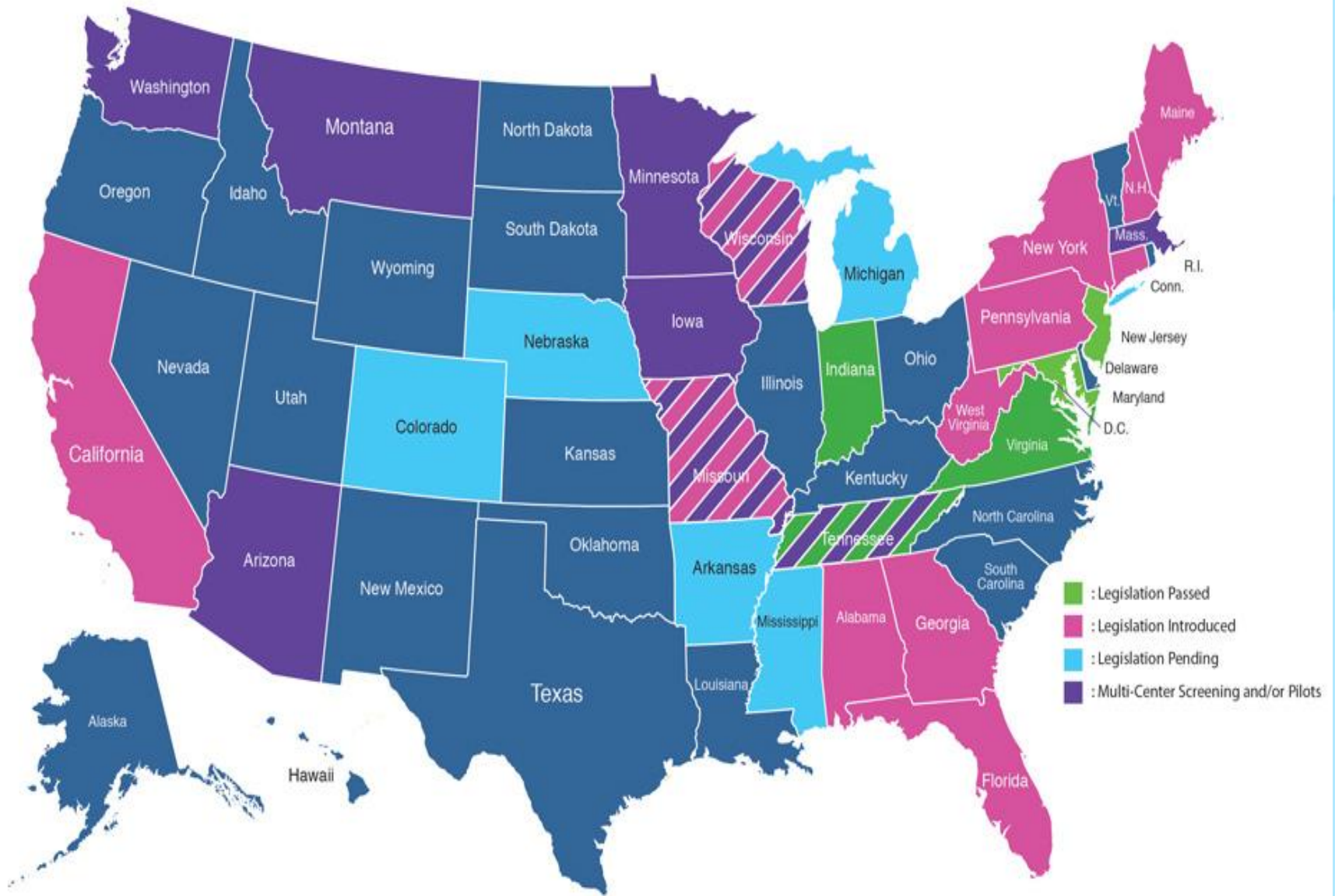
- ❑ **Screening Standards and Infrastructure:** HRSA to guide the development of screening standards/infrastructure
- ❑ **Education and Training:**
  - HRSA to fund the development of appropriate education/training materials
  - FDA to provide guidance to industry and FDA staff on pulse oximeters
- ❑ **Research:** NIH to determine the screening technology, diagnostic processes, care provided and health outcomes
- ❑ **Surveillance:** CDC to monitor infant mortality and other health outcomes (clinical utility and program evaluation)

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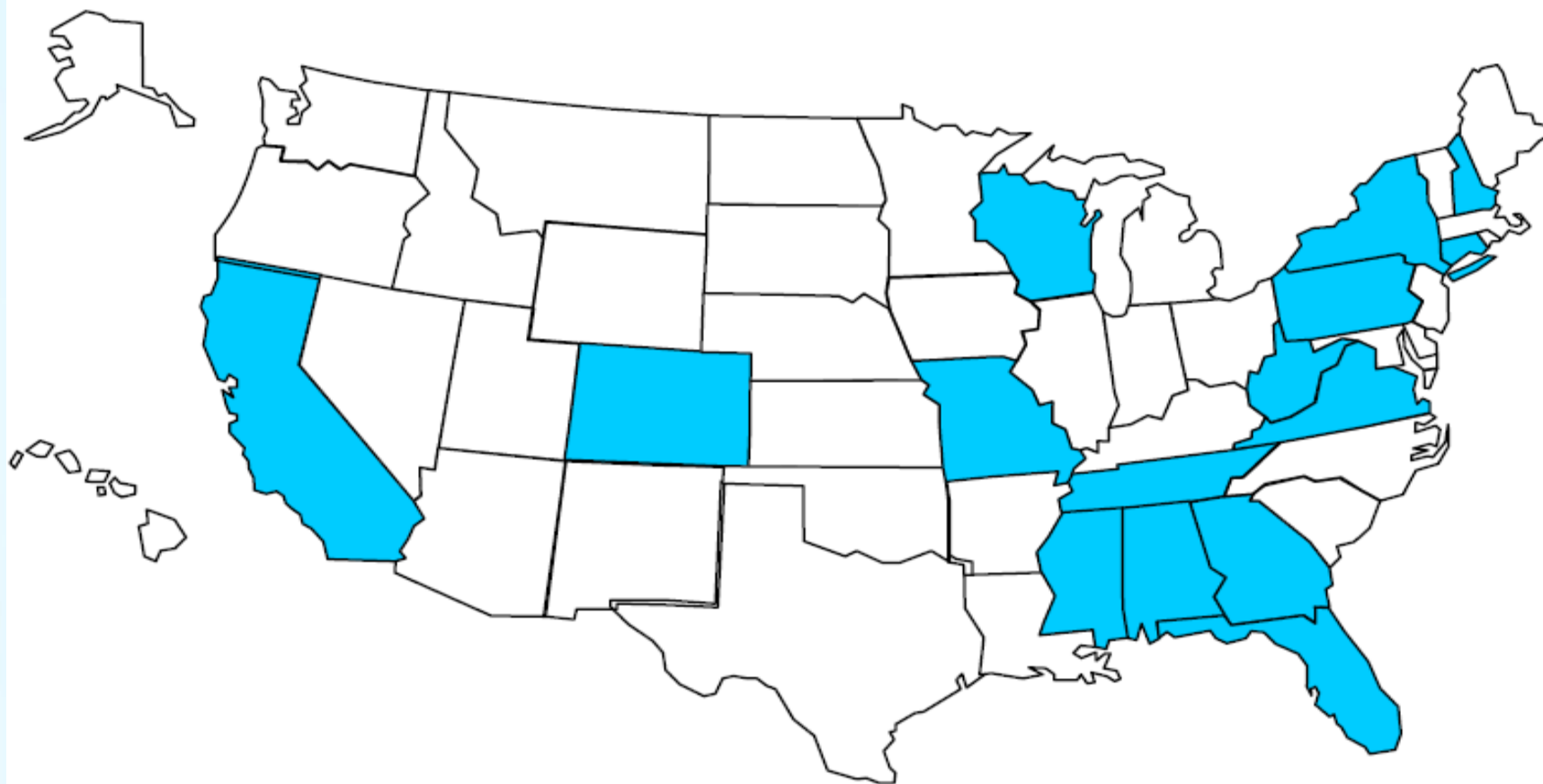
# CDC Activities

- ❑ **Evaluate state surveillance and tracking**
  - National Birth Defects Prevention Network (NBDPN) survey of states
  - Collaboration with New Jersey, Epi-Aid to assess surveillance, tracking
- ❑ **Conduct a cost-effectiveness analysis CCHD screening**
  - Collaboration with New Jersey, Econ-Aid to assess total cost burden
  - Ongoing evaluation activities
- ❑ **Leverage an electronic health record framework**
  - NCBDDD working group on EHRs
  - Creating a strategic plan on leveraging EHRs for public health activities, focus on CHD
  - Collaboration with National Library of Medicine



# Bills Introduced During 2011-2012 Legislative Sessions

(As of February 29, 2012)



STATE  
GOVERNMENT  
AFFAIRS 

American Academy  
of Pediatrics



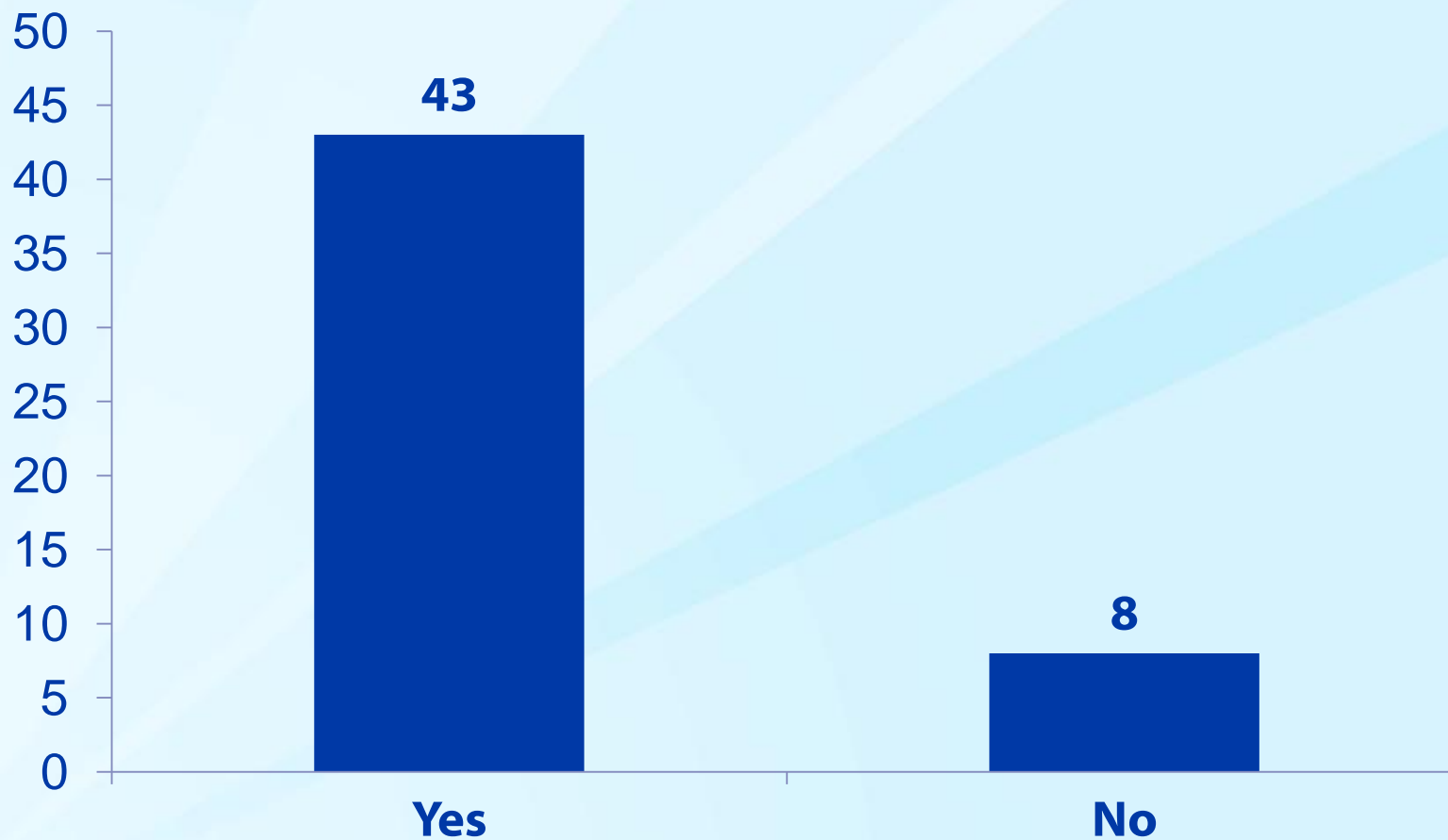
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# **Survey of Birth Defects Surveillance Programs**

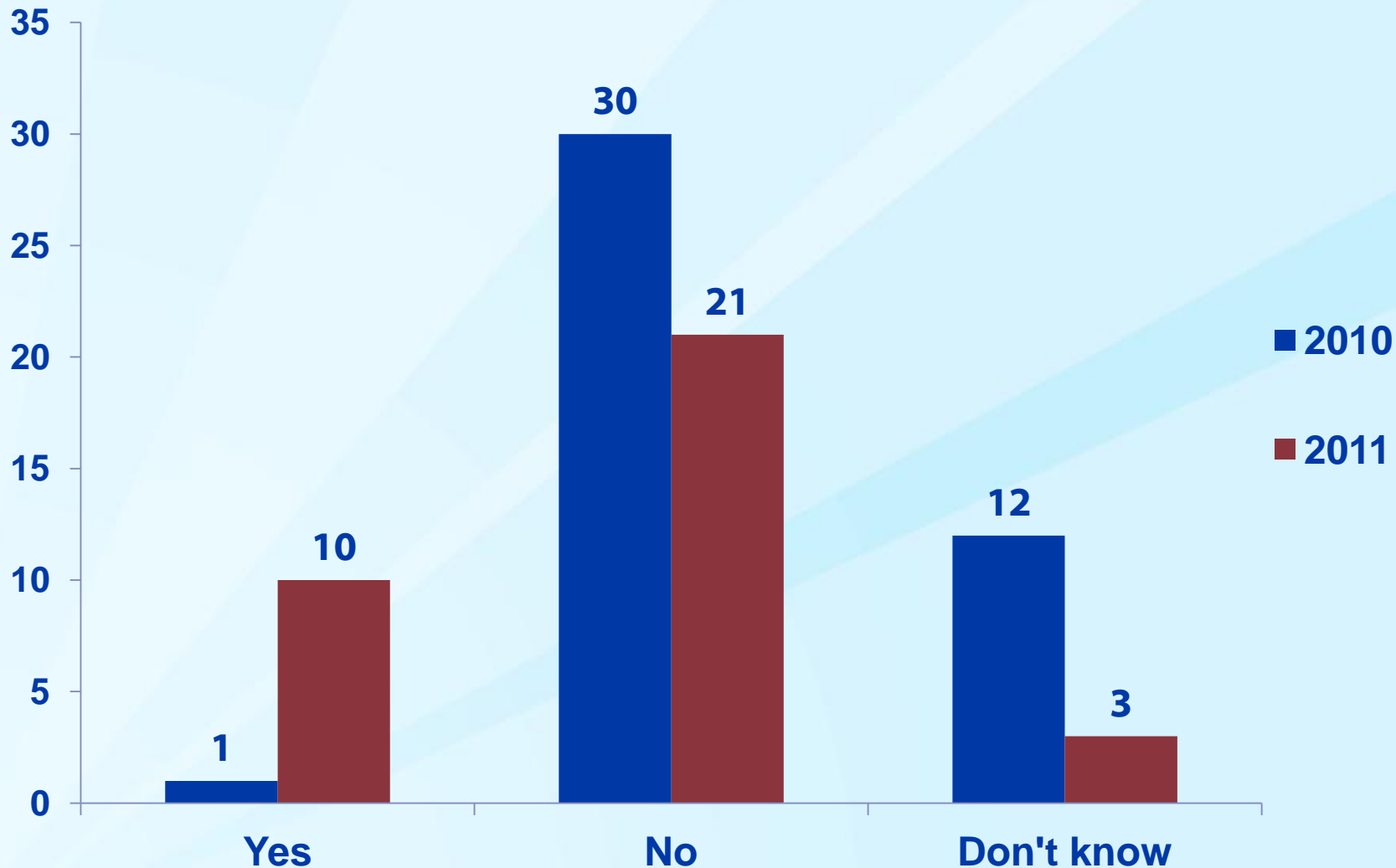
- ❑ To assess the potential role of state birth defects surveillance programs with screening for critical congenital heart disease (CCHD)**
- ❑ First distributed in October 2010 by NBDPN**
- ❑ Revised in November 2011 following the addition of CCHD to uniform newborn screening panel**
- ❑ States were asked to confirm or change responses from 2010**



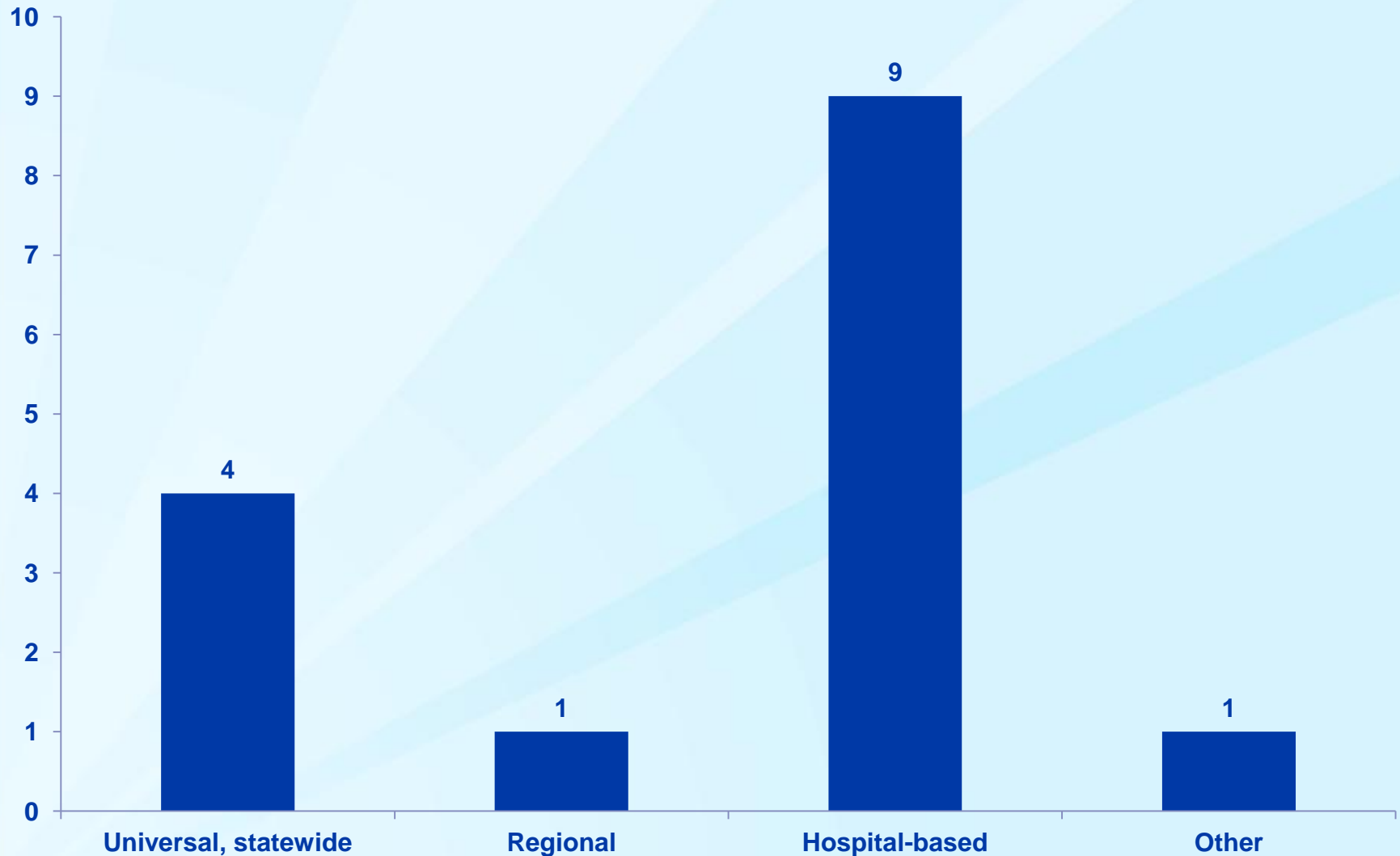
## Does your state have a birth defects surveillance program?



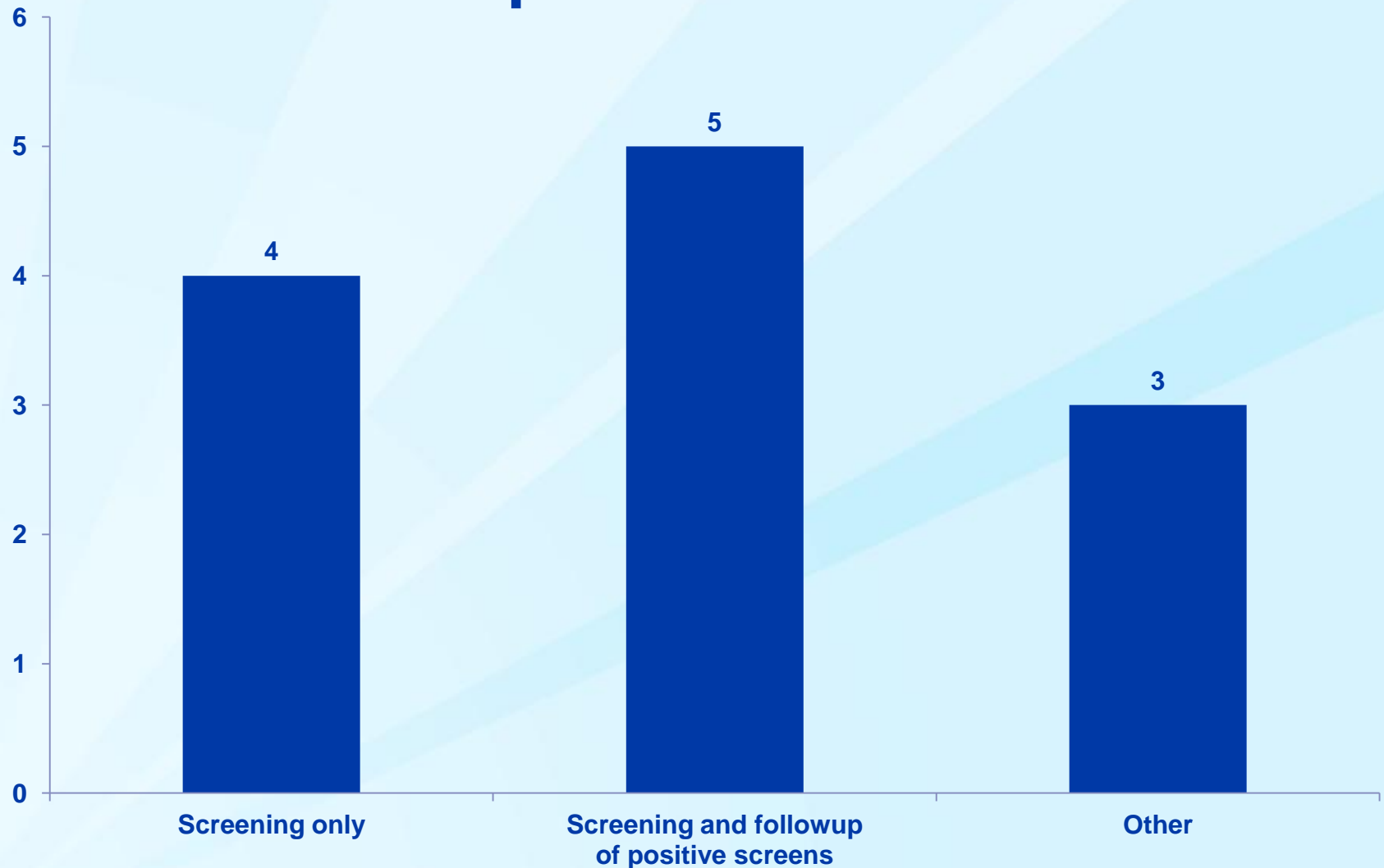
# Is your state engaged in pulse oximetry screening for CCHD?



# If state is engaged in screening activities, is the screening:



# If your state is engaged in screening activities, what components are included?



## **If your state adopts NBS for CCHD, how could the birth defects surveillance program assist with the confirmed cases of CCHD?**

<b>Possible Options for Assistance</b>	<b>Number of States</b>
<b>Link children identified by screening to support services</b>	<b>16</b>
<b>Report on healthcare utilization by affected children</b>	<b>13</b>
<b>Report on support services utilization by affected children</b>	<b>7</b>
<b>Report on enrollment of affected children into special education services</b>	<b>1</b>
<b>Other</b>	<b>8</b>

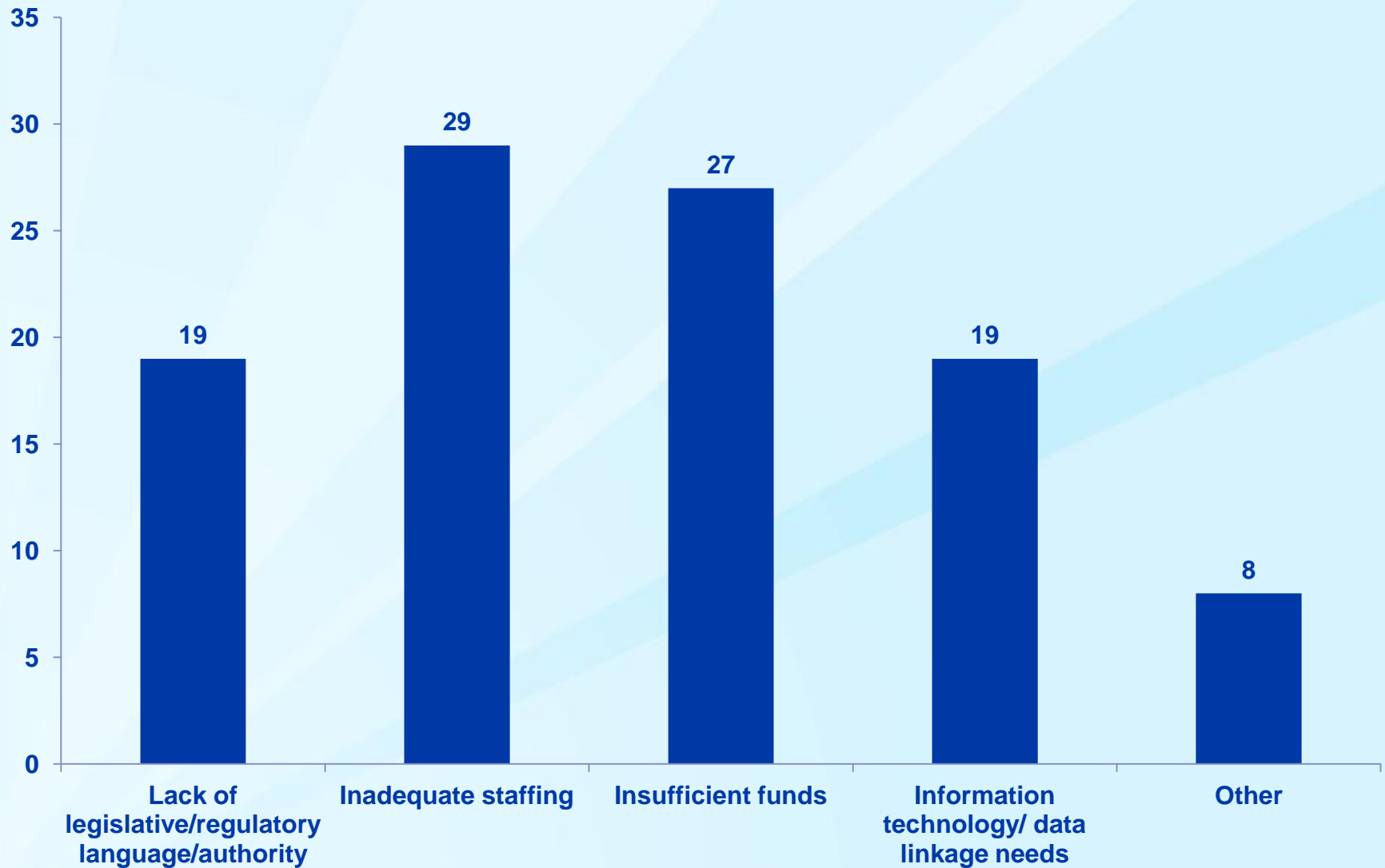
## **How could the birth defects surveillance program assist with evaluation of CCHD newborn screening?**

<b>Possible Options for Assistance</b>	<b>Number of States</b>
<b>Evaluate mortality associated with CCHD</b>	<b>28</b>
<b>Evaluate morbidities associated with CCHD</b>	<b>16</b>
<b>Evaluate interventions associated with CCHD</b>	<b>11</b>
<b>Compare outcomes of children with CCHD</b>	<b>14</b>
<b>Evaluate all true and false positive screens</b>	<b>13</b>
<b>Evaluate false negative screens</b>	<b>13</b>
<b>Assist with economic evaluation of screening</b>	<b>8</b>
<b>Other</b>	<b>8</b>

## What is the working relationship between your state's birth defects surveillance program and newborn screening program?

<b>Relationship</b>	<b>Number of States</b>
<b>Organizationally located together</b>	<b>11</b>
<b>Contained within the same bureau/program</b>	<b>15</b>
<b>Physically located in the same building</b>	<b>14</b>
<b>Currently share same database/data system</b>	<b>8</b>
<b>None/No working relationship</b>	<b>5</b>
<b>Other</b>	<b>10</b>

# What are the likely barriers in your state to your program's involvement with newborn screening for CCHD?





## Summary

- ❑ **Many state birth defects surveillance programs have the data needed to evaluate implementation of CCHD screening**
- ❑ **Opportunity for collaboration between state newborn screening and birth defects programs**
- ❑ **Barriers to involvement in CCHD screening exist in many states regardless of legislative activity**

## Resources

- ❑ **CDC, National Center on Birth Defects and Developmental Disabilities: Screening for Critical Congenital Heart Defects**
  - <http://www.cdc.gov/ncbddd/pediatricgenetics/cchdscreening.Html>
- ❑ **National Birth Defects Prevention Network**
  - <http://www.nbdpn.org/>
- ❑ **Congenital Heart Public Health Consortium**
  - <http://chphc.org/hostedsites/Pages/default.aspx>
- ❑ **Toolkit for Providers: Children's National Medical Center Congenital Heart Screening Program**
  - <http://www.childrensnational.org/PulseOx/HealthCareProvidersResources.aspx>

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## **AMCHP**

Kate Howe

## **NY State DoH**

Chris Kus

## **NBDPN**

Glenn Copeland

## **All state BD & NBS Programs**



# Thank You

**For more information please contact Centers for Disease Control and Prevention**

1600 Clifton Road NE, Atlanta, GA 30333

Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348

E-mail: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov) Web: [www.cdc.gov](http://www.cdc.gov)

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