

CRITICAL OPPORTUNITIES FOR PUBLIC HEALTH LAW:

Title: Critical Congenital Heart Defects and Pulse Oximetry

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A PROBLEM

Congenital Heart Defects cause nearly ¼ of deaths due to birth defects in infants.

Nearly 5000 babies are born each year 7 specific Critical Congenital Heart Defects or Critical Congenital Heart Disease (CCHD).

Babies with CCHD are at significantly higher risk of disability or death if not diagnosed shortly after birth.

However, there is a low-cost, non-invasive screening procedure, called pulse oximetry, that is effective in detecting CCHD.

Despite the availability of pulse oximetry not all babies are screened for CCHD. Only certain states require pulse oximetry screening for CCHD.

WHERE DOES LAW FIT IN?

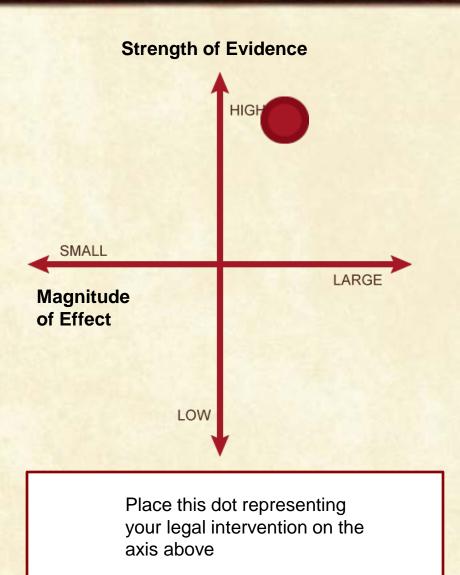


Statutes and regulation can make CCHD screening mandatory, but very few states have done so.

Newborn screening is a state power and as such the federal government has only an advisory role. By adopting pulse oximetry screening for CCHD into the Recommended Universal Screening Panel (RUSP) the Department of Health and Human Services (DHHS) has gone as far as they can.

It falls to the states to pass new legislation or make new regulation that requires CCHD screening.

EVIDENCE SUPPORTING THE REFORM



Pulse oximetry screening has been endorsed by the American Academy of Pediatrics (AAP) for its effectiveness as a preliminary screening mechanism for CCHD.

To date no studies have been done on the specific effect new laws have when mandating CCHD screening, however, large cohort studies in Europe showed the promise of using universal pulse oximetry screening for all newborns.

A WAY FORWARD



- Pulse oximetry is low cost and non-invasive as CCHD initial screening.
 - Follow up, done with echocardiography, is also relatively affordable.
- Politically, newborn screening measures, especially non-invasive and non-genetic tests like pulse oximetry, are not very controversial.
 - Several states have already mandated this screening for CCHD.
- Some issues of access and follow up screening present challenges going forward, but are already being studied by DHHS and the AAP