

National Newborn Screening Contingency Plan (CONPLAN, V2)

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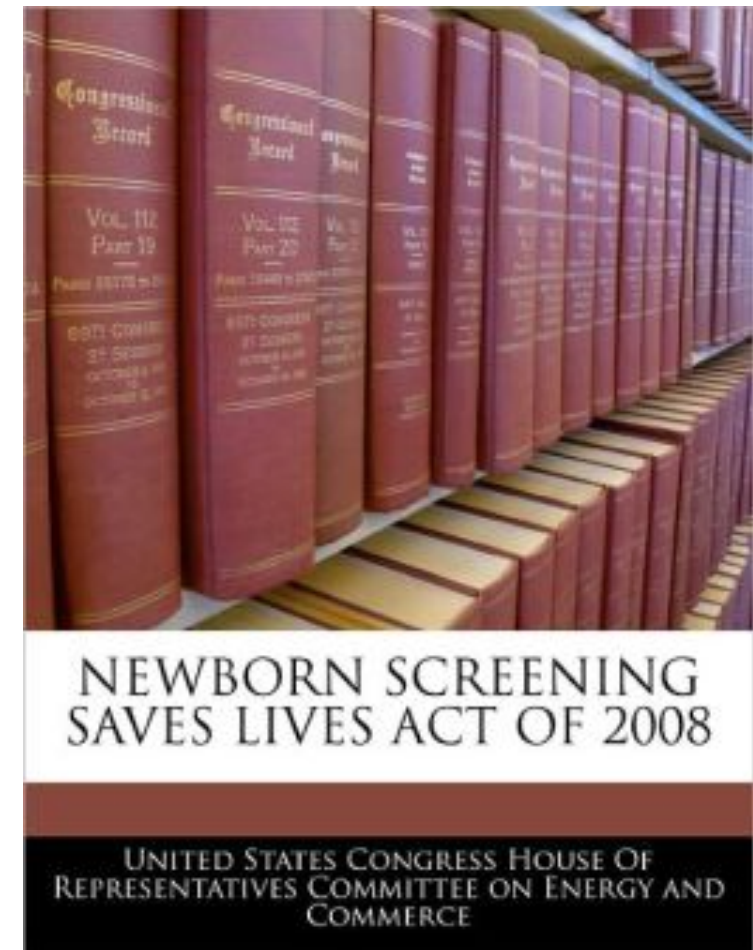
Advisory Committee on Heritable Disorders in Newborns and Children



NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**

Background

- Newborn Screening Saves Lives Act of 2008
 - Directs CDC – with HRSA and State Agencies – to develop a national NBS contingency plan for use by a state, region, or consortia of states in the event of a public health emergency.
- 2008 – CDC/HRSA Workshop
 - Federal partners; State public health programs (including newborn screening programs, state labs, maternal child health programs); State emergency preparedness programs; and Clinicians
- 2010 – CONPLAN, VI published



Background

- Newborn Screening Saves Lives Reauthorization Act of 2014
 - The plan shall be updated as needed and at least every five years.
- In 2015, AMCHP partnered with CDC, HRSA, APHL, and expert stakeholders to update the national NBS CONPLAN.
- Advisory Committee
 - Newborn screening programs
 - Public Health Labs
 - Regional Collaboratives
 - Family Voices
 - Newborn screening HIT
 - Metabolic Specialists
 - Title V
 - AAP
 - AMCHP
 - APHL
 - ASTHO
 - CDC
 - HRSA
 - March of Dimes
 - NACCHO

IC

113TH CONGRESS
2D SESSION

S. 1417

IN THE HOUSE OF REPRESENTATIVES

JANUARY 31, 2014

Referred to the Committee on Energy and Commerce

AN ACT

To amend the Public Health Service Act to reauthorize programs under part A of title XI of such Act.

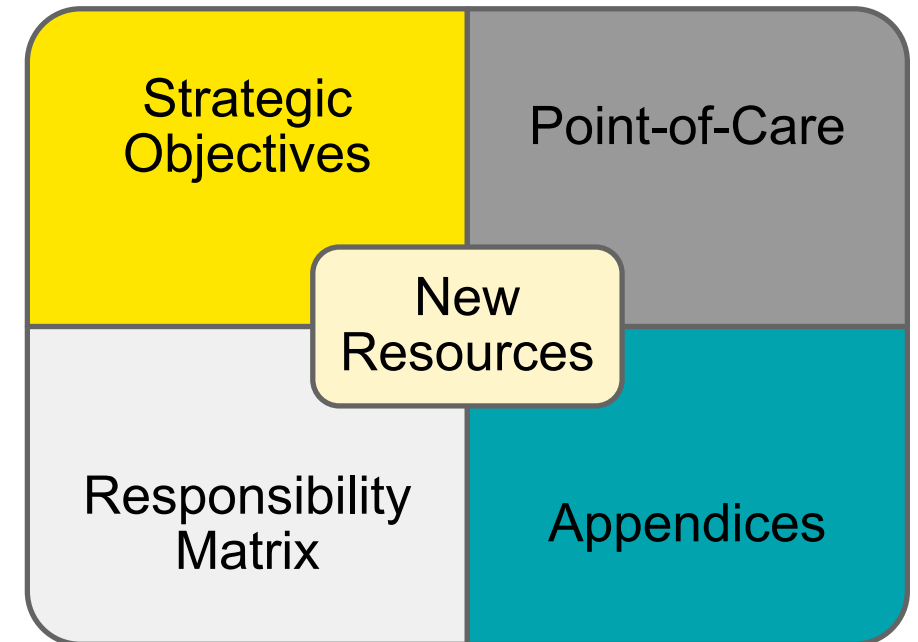
1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

2

1 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

Update Process & Recommendations

- Advisory Committee Calls
- Public Comment Survey (Winter 2015/16)
- In-person working meeting
- Subcommittee revisions and resource development
- Submission of revision recommendations to federal partners
- CDC and HRSA review
- Publication August 2017



Strategic Objectives

- Ongoing communication to families, providers, birth facilities, and agency staff is ensured.
- Families are educated about newborn screening.
- A framework for screening (blood spot, hearing, and CCHD) and specimen collection is established.
- Specimens are shipped to the designated newborn screening laboratory site.
- Specimens are processed and tested.
- Screening results are reported to the newborn screening follow-up program and physicians and families.
- Diagnostic testing is performed for infants with positive screening results for time-critical disorders.
- Availability of treatment and management resources is ensured.
- Carry out other activities determined appropriate by the HHS Secretary.

Ongoing communication to families, providers, birth facilities, and agency staff is ensured.

An effective newborn screening communication network is established.

A plan for communications to all stakeholders during an emergency event is established.

Multiple communication modalities are in place and utilized.

Families are educated about newborn screening.

Families know about the need for newborn screening.

Families with newborns who are screened know how to obtain newborn screening results.

Families know what to do in response to newborn screening results.



Screens conducted; Specimens are collected and transported.

Specimens shipped to designated newborn screening laboratory site within 24 hours.

Specimens are processed.

Screening results reported to physicians and families.

Diagnostic testing is performed.

Availability of treatment and management resources is ensured.

What should be available?

- NSQAP-certified blood spot collection cards.
- Other materials required for blood spot collection hearing screening and pulse oximetry CCHD.
- Training on how to conduct blood spot and point-of-care screenings.
- Training and processes on how to collect and ship dried blood spot specimens.

How do you manage en-route missing dried blood spot (DBS) specimens?

- En-route DBS specimens to impacted labs should be redirected to appropriate labs.
- Missing/not shipped DBS specimens should be recognized, and new specimen obtained.

What should be secured?

- Integrity of specimens and records of all DBS specimens sent to and received by back-labs.
- All DBS specimens are processed.
- Address emergency situation to preserve or restore capacity.

What decisions should be made?

- The need for additional/alternative capacity.
- Appropriate internal and external stakeholders to notify.
- Whether to activate back-up lab system for managing external specimens.

What communication lines should be established?

- Screening/receiving laboratories, hospitals and NBS follow-up coordinator.
- NBS program and physician or healthcare provider.
- If healthcare provider is not available, communication between NBS program and families should occur.

What communication lines should be established?

- All screening specimens and results.
- Infants who are not screened.

What actions should be taken?

- Diagnostics testing and tracking is ensured.
- Diagnosis is established.
- Results are communicated to the healthcare provider, family, and NBS screening program.

What should be identified and confirmed for infants with diagnosis?

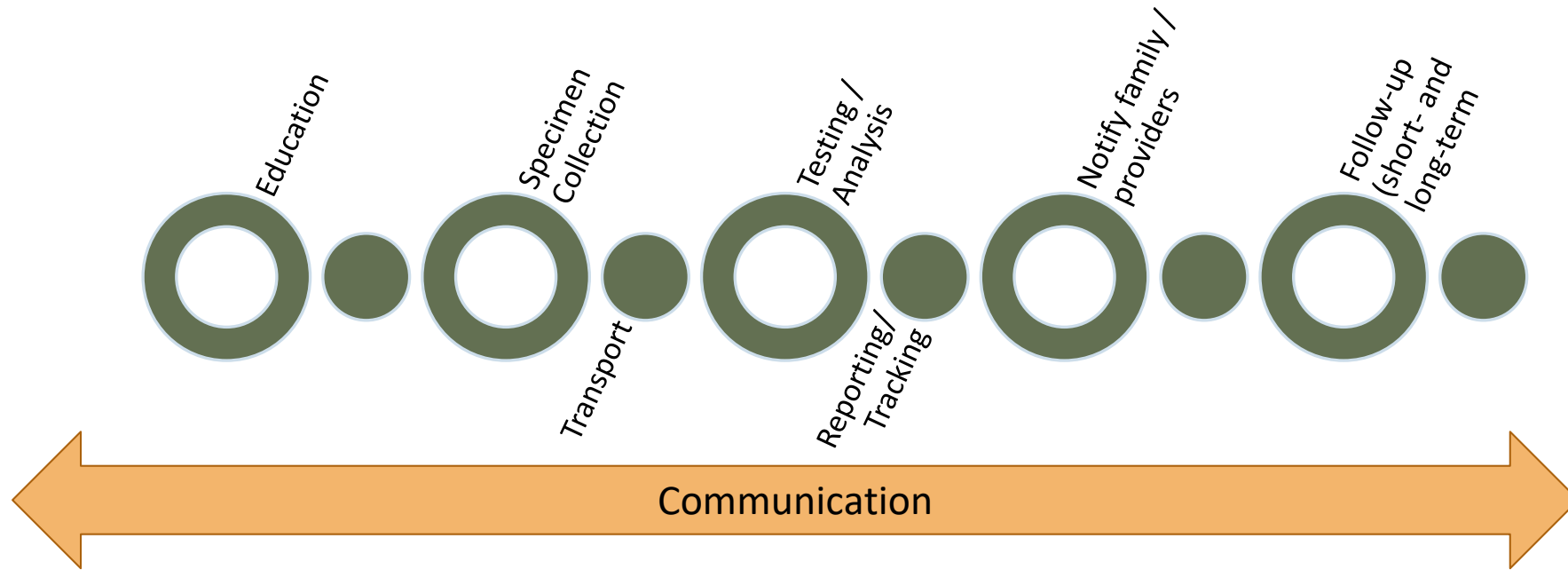
- Appropriate treatment, service and/or intervention.
- Access to and connection with a medical home.
- Appropriate multi-disciplinary services through an established medical home.
- Connection to long-term follow-up program and services, if applicable.

Carry out other activities determined appropriate by HHS Secretary.

Preparedness issues are identified and addressed for NBS systems.

Implementation, maintenance, and validation of the NBS Contingency Plan are performed by HHS.

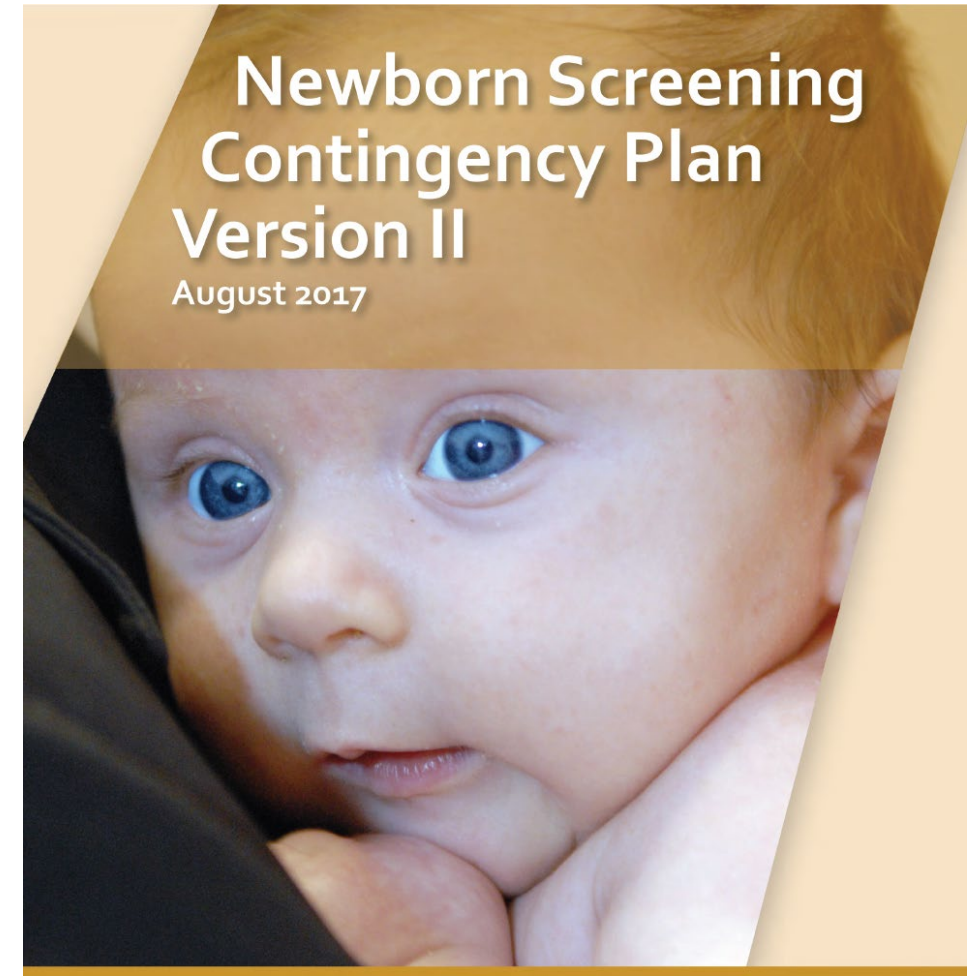
Plan must be Usable



- Vulnerability Assessment
- Planning Assumptions
- Essential Functions
- Preparation Documents
- Training and Exercise
- Funding guidelines
- MOUs
- Case Examples
- How to connecting with other states / supports

Next Steps (2017)

- ACHDNC Report to Congress 2013-2017
- CDC/HRSA Clearance
- Get the Band Back Together
 - Advisory Committee Dissemination Plan
 - Publish
 - Review/Revise
- Work with Programs to Develop, Implement, and Maintain



North Carolina NBS COVID-19 Experiences

Resources

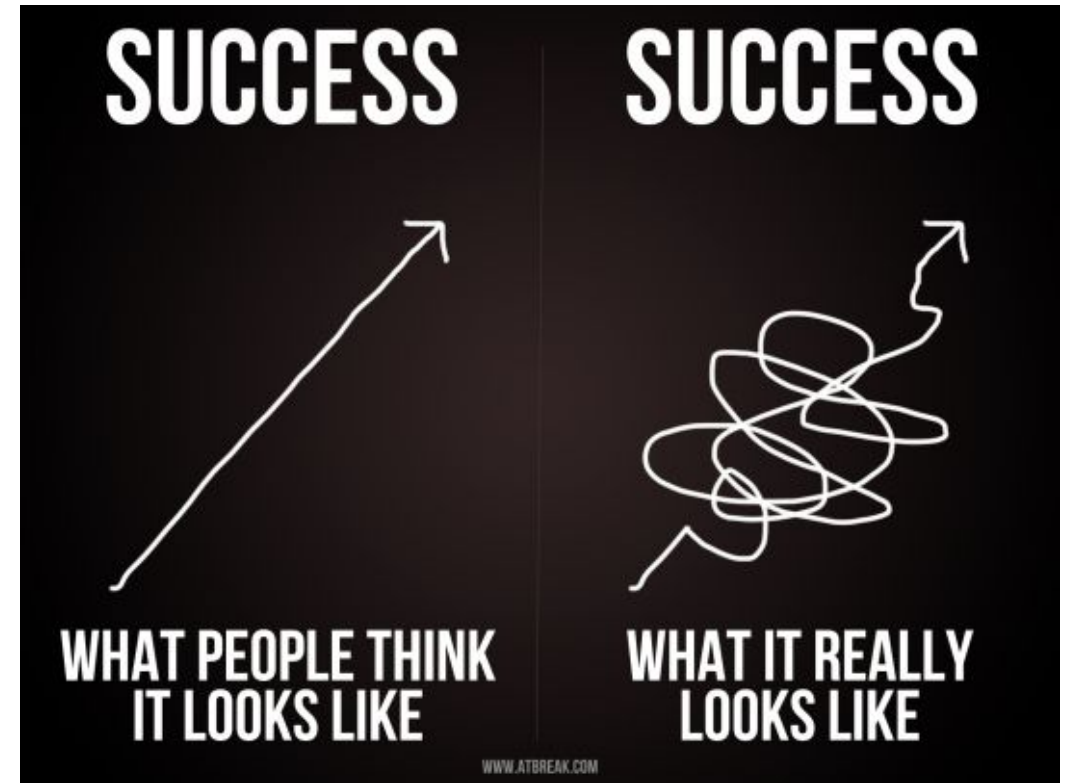
- Reallocation to other areas
- Supply chain challenges

Courier

- Impact of staff exposures
- Volume delays

Project Management

- Resource reallocation
- “Business decision makers were otherwise occupied”



How Programs Feel



<https://blog.frontporchforum.com/2013/05/03/help-by-the-truckload/>

How Programs Operate



<https://www.pe.com/2017/07/29/freight-rail-provides-an-infrastructure-model-for-california/>

What Programs Need



<https://www.youtube.com/watch?v=Q1bOY3JGsTs>

Next Steps 2020

- Assure NBS is Part of Lessons Learned from COVID-19 Response
- Contingency Planning ≠ Preparedness
- Need to Identify Cranes
- Whole System Approach

Newborn Screening System

