

**Department of Health and Human Services**

**Newborn Screening  
Contingency Plan (CONPLAN)**

July 2010

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## EXECUTIVE SUMMARY

### Background

Each year, more than 4 million babies born in the United States are screened at birth by state newborn screening programs to detect some conditions that may threaten their long-term health. Of these, approximately 6,000 infants born each year are diagnosed with detectable and treatable disorders. If diagnosed early, these conditions can be successfully managed or treated to prevent severe and often lifelong health consequences. Each state independently determines the conditions and screening procedures for its screening program. Prior to 2006, states varied widely on the number of conditions for which infants were tested. Moving toward standardization, in 2006, the American College of Medical Genetics (ACMG) completed a report commissioned by the Health Resources and Services Administration (HRSA). The ACMG report recommended that every baby born in the United States be screened for 29 specific core conditions, and that states should report test results for any of the additional 25 specific secondary conditions that may be identified incidentally during the course of screening for the core panel. The Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children has endorsed the report and its recommendations.

### The Newborn Screening Saves Lives Act of 2008

On April 24, 2008, *The Newborn Screening Saves Lives Act of 2008* became public law (H.R. 3825; Report No. 110-570)).

This law directs the Centers for Disease Control and Prevention (CDC), in consultation with HRSA and the State Departments of Health (or related agencies), to develop a national newborn screening contingency plan for use by a state, region, or consortia of states in the event of a public health emergency. This plan was required to be developed within 180 days of enactment of the legislation, by October 21, 2008.

Contingency planning for an emergency helps to ensure the availability of critical resources, the continuity of operations and sets standards for entities participating in the activation of the plan. Adhering to the established standards and maintaining continuity of testing and follow-up, play critical roles in the screening, diagnosis, referral, and treatment of disorders identified in newborn screening, especially during a public health emergency.

### Concept of Operations

Newborn screening is organized as a system that includes the following: screening, short-term follow-up, diagnosis, treatment and management, and evaluation and education. The newborn screening program's efficiency and effectiveness depend on the smooth integration of sample collection, laboratory testing, follow-up diagnosis, timely treatment, and tracking of outcomes. Newborn screening is a system that intersects both the public and private sectors.

Most sectors of government, as well as many successful corporations in the private sector, have developed plans to ensure continuity in the event of disaster or emergency. These plans are generally referred to as "Continuity of Operations," or COOP. A COOP for a newborn screening program and its public health laboratory should have two basic features: 1) A COOP provides a comprehensive, pre-identified list of all core testing, support activities, and supplies that must be maintained if the laboratory experiences a partial or complete operational disruption. 2) A COOP provides a prearranged plan of action to ensure that all these core activities are continued without delay.

In this document we use the terms contingency plan and continuity of operations interchangeably. This document is intended to be used as a framework by state and local health agencies, laboratories, clinicians and other organizations that are part of the newborn screening system in the United States. Each organization may use the applicable sections of this framework to create their COOP.

## Strategic and Operative Objectives

To properly prepare for contingency operations, it is necessary to describe beforehand what actions are required to ensure newborn screening can be accomplished. Each strategic objective, as provided in the Act, requires supporting actions to be accomplished. The following outlines the major supporting actions that each public health official should consider when planning and preparing for newborn screening contingency operations. The responsible entities for each action are outlined in Appendix B: Responsibilities Matrix. Each state should also ensure that their newborn screening contingency plan is integrated into the overall state preparedness plan.

Each strategic objective is supported by specific operational objectives, which are further supported by specific activities. Each activity has a party or entity that is responsible for ensuring proper implementation of that supporting activity. Further, it is incumbent upon each responsible entity to develop and maintain specific Standard Operating Procedures (SOPs) that detail how each activity is executed within their jurisdiction or scope of responsibility. SOPs generally detail who, what, why, when, where, and how and should be exercised and reviewed or updated on a regular basis to ensure they reflect the current method in which the entity operates.

### Strategic Objectives

- 1: A framework for specimen collection is established.
- 2: Specimens are shipped to the designated newborn screening laboratory site.
- 3: Specimens are processed.
- 4: Screening results are reported to the newborn screening follow-up program and physicians and families.
- 5: Positive diagnostic screening results are confirmed.
- 6: Availability of treatment and management resources is ensured.
- 7: Families are educated about newborn screening.
- 8: Carry out other activities determined appropriate by the HHS Secretary.

### Common Roles and Responsibilities

#### a. Key HHS Roles and Responsibilities

*National Disaster Medical Service (NDMS)*, Department of Health and Human Services (HHS): The NDMS is supplemented by State and local medical resources during disasters or major medical emergencies. Medical response is led by HHS, which coordinates the Disaster Medical Assistance Teams that are groups of intermittent federal employees who volunteer to be on a designated team for NDMS. Teams of 35 with a range of health and medical skills are typically deployed. As it relates to newborn screening and genetics patients, there are two pediatric teams in NDMS.

*Centers for Disease Control and Prevention (CDC)*: The Office of Public Health Preparedness and Response (OPHPR) has primary oversight and responsibility for all programs that comprise CDC's terrorism preparedness and emergency response portfolio. The CDC National Center on Environmental Health (NCEH) provides laboratory support to newborn screening programs. CDC takes an active role in quality assurance programs for state newborn screening programs and works with the Association of Public Health Laboratories (APHL) in that regard. A key element in programmatic activity at the CDC is the National Center on Birth Defects and Developmental Disabilities (NCBDDD), which provides genetic and public health scientific expertise and represents CDC on the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC).

*Health Resources and Services Administration (HRSA):* HRSA's Maternal and Child Health Bureau (MCHB) oversees the Title V Maternal and Child Health Services Block Grant, which includes State Formula Block Grants, Special Projects of Regional and National Significance grants and Community Integrated Service Systems grants. Through these grants, HRSA/MCHB oversees both dried blood spot and hearing screening programs, assuring that children receive timely follow-up and services. The largest portion of Title V goes to the states to meet critical challenges in maternal and child health, including newborn screening, and monitoring system of care for infants, children, youth, women of all ages and pregnant women and their families. HRSA/MCHB seeks a nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting.

**b. Non-Federal Responsibilities**

Newborn Screening is a system cutting across all levels of governmental public health, hospitals, health plans, manufacturers, pharmacists, clinicians, advocacy organizations and other entities. Staff members who will be providing newborn screening should be made aware of the following:

1. State and local coordination requirements.
2. Non-governmental organization requirements.
3. Private sector coordination requirements.
4. Key federal decisions.
5. Actions required or prohibited of the federal government.

**State Plan Development**

Each State Health Official is responsible for newborn screening. In utilizing the framework provided here the state will be able to develop pre-alert or activation responsibilities with the other key newborn screening entities within their jurisdiction, including the State Title V Maternal and Child Health Program Director, hospitals, geneticists, pediatricians and other providers, and manufacturers and suppliers of materials. All these parties, along with parents and other community groups, should participate in the development and testing of recommended plans.

Planning exercises conducted at routine intervals will help identify pitfalls in implementation.

**Effective Date, Implementation and Revisions**

This Newborn Screening Contingency Plan builds upon the efforts of many concerned stakeholders across the public health spectrum. This document seeks to build upon the work done by many caring professionals around the country and is intended to enhance, not substantively nor dramatically alter the methodology or systems used in newborn screening.

The effective date of this plan will be two weeks after final publication, following signatures from the Director of CDC and the Director of HRSA. This plan will be updated and renewed on an as-needed basis. This plan shall not be altered, changed, modified, or amended except by written consent of both parties to the plan.

As the field of emergency preparedness is an evolving one, and the science and systems involved in newborn screening are always improving, this document is subject to amendments based on changes to the standard operating procedures in stable situations, and based on information gathered during and after a disaster. Such amendments, shall however, will be subject to same level of scrutiny as in the preparation of this initial document.

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## I. SITUATION

In the United States today, our goal is that every infant is screened at birth for a number of conditions that, if left untreated, can cause death, disability, mental retardation and other serious illnesses. Universal newborn screening is a system that encompasses screening, diagnosis and follow-up, management and treatment, as well as education and evaluation. Newborn screening represents an effective way in which to diagnose conditions that otherwise would go undetected in early infancy.

To enhance and support universal newborn screening, *The Newborn Screening Saves Lives Act of 2008* (hereinafter referred to as the 'Act') became public law (H.R. 3825; Report No. 110-570) on April 24, 2008. During the creation of this Act, Congress found the following:

- (1) Each year, more than 4 million babies born in the United States are screened at birth by state and private laboratories to detect these conditions.
- (2) Because of a lack of national newborn screening guidelines, however, each state independently determines the conditions and screening procedures for its screening program. Therefore, there is considerable variation among screening panels from state to state. Although a newborn might be screened and treated for a debilitating condition in one state, in another state, the condition might be undetected, resulting in permanent disability or even death.
- (3) Approximately 6,000 infants born each year are diagnosed with detectable and treatable disorders. If diagnosed early, these conditions could be successfully managed or treated to prevent severe and often lifelong health consequences.
- (4) An important step in contingency planning for newborn screening is agreement on standards among those entities participating in contingency planning. Before 2006, and in the absence of national newborn screening guidelines, testing for infant conditions varied widely among states. Moving toward standardization, the American College of Medical Genetics (ACMG) completed a report in 2006 commissioned by the Health Resources and Services Administration (HRSA). The ACMG report recommended that every baby born in the United States be screened for 29 specific core conditions, and that states should report test results for any of the additional 25 specific secondary conditions that may be identified incidentally during the course of screening for the core panel. The HHS Secretary's Advisory Committee on Heritable Disorders in Newborns and Children has endorsed the report and its recommendations.
- (5) Currently, 26 states and the District of Columbia require infants to be screened for the 29 core conditions. (As of May 2010, all states screen for the 28 conditions identified by dried blood spot screening)
- (6) Adhering to these standards for newborn screening and maintaining testing is critical to the screening, follow-up, diagnosis, referral, and treatment of these conditions, especially during a public health emergency. Currently, there is no national contingency plan for maintaining a standardized process and continuity of newborn screening systems following a public health emergency.

Under Section 1115 of the Act, CDC was directed to consult with the Administrator of HRSA and State Departments of Health (or related agencies) to develop a national contingency plan for newborn screening within 180 days of enactment of the Act for use by a state, region, or consortia of states in the event of a public health emergency.

### a. Purpose

To facilitate collaboration and efficiency among federal agencies and state, local, territorial, tribal, and regional efforts to screen newborns for identified conditions during a public health emergency.

This effort is limited to those areas of the newborn screening system (screening test, diagnosis and follow-up, treatment and management, education and evaluation) for which the state public health agency assumes an oversight role.

Although certain aspects of this plan will formalize processes, procedures, and agreements, it will also contain guidance. Public health officials are free to exercise the details of issues, such as continuity of operations, outside the guidelines offered in this document.

## **b. Background**

Interest in the effective implementation of newborn screening has commanded a significant place in the United States public health arena for decades. For example, the efforts of non-governmental organizations, such as the March of Dimes, have championed the cause of newborn health for almost a century. And in July 2008, the CDC's Newborn Screening Quality Assurance Program (NSQAP) celebrated its 30<sup>th</sup> anniversary. Although the NSQAP has played an important role in the *quality assurance* aspect of newborn screening, it was the determined efforts of several U.S. Senators, non-governmental organization advocacy, and a national tragedy to address newborn screening contingency planning.

In 2004, a subcommittee of the Association of Public Health Laboratories (APHL) Newborn Screening and Genetics in Public Health Committee was established to develop a framework to assist public health laboratories prepare for, and respond to, disasters caused by nature, terrorism, and interruptions of testing materials and supplies. The subcommittee designed a checklist that outlines the various elements public health laboratories must address to prepare for disasters that disrupt newborn screening program operations. A generic Memorandum of Understanding/Agreement (MOU/MOA) ([Appendix C](#)) was developed to include elements for consideration by states that may need assistance from other states using a mutual assistance agreement.

In 2005, Hurricanes Katrina and Rita destroyed Louisiana's state public health laboratory eliminating the state's ability to perform newborn screening testing. The chief of the Louisiana Public Health Laboratory determined that the state's newborn screening program was one of the state's highest public health priorities. Fortunately, the Iowa public health newborn screening laboratory was able to rapidly assume the screening of Louisiana's newborns. Following the hurricanes, HRSA, the HRSA-funded Regional Genetic and Newborn Screening Service Collaboratives, their national coordinating center, and APHL initiated a process to create regional newborn screening emergency preparedness plans.

During the past several years, APHL members and the regional collaboratives have experienced newborn screening service interruptions caused by natural disasters and manufacturer inability to provide testing materials. APHL served as the central point of contact during these emergencies and assisted programs to maintain services. Contingency planning can better prepare those involved in newborn screening for maintaining operations during an emergency. The regional collaboratives, HRSA and the APHL Newborn Screening and Genetics in Public Health Committee initiated a major effort to define the critical elements of an emergency newborn screening contingency plan, which was a precursor to Section 1115 of the *Newborn Screening Saves Lives Act*.

Newborn screening is an essential, preventive public health program for the early identification of medical conditions that can lead to catastrophic health problems. If left untreated, the cost of these conditions is enormous, both in human suffering and in economic terms. Therefore, continuity of services is a priority for newborn screening programs.

## **c. Authorities**



- [The Newborn Screening Saves Lives Act of 2008](#)
- *Title V of the Social Security Act of 1935*
- *Title XXVI of the Children's Health Act of 2000, "Screening for Heritable Disorders"*
- *Public Health Service Act of 1944*

**d. Threat**

(1) A thorough analysis of state and site vulnerabilities provides a list of threats that may disrupt normal public health functions. This includes newborn screening program operations within laboratory facilities (e.g. laboratory testing) and within the community (e.g. patient follow-up, treatment). Such threats fall into several general categories:

- Extreme weather conditions;
- Major equipment failure;
- Prolonged personnel staffing issues;
- Extensive building damage;
- Compromised building utilities;
- Failed communication systems;
- Shortage of testing materials and supplies;
- Civil disturbance;
- Acts of terrorism.

Each public health newborn screening program should develop a comprehensive list specific for its own facility.

(2) Among possible threats, the vulnerability assessment should consider the potential impact of criminal activity on newborn screening program operations. To determine the level of this risk, it is important to review the effectiveness of any crime mitigation methods currently being used at the facilities where newborn screening programs operate, such as surveillance cameras, security guards, access control, locking systems, screening or detection equipment, and digital tracking systems.

(3) When assessing vulnerability, it is also important to consider threats from secondary sources. For the newborn screening system, for example, these would include non-laboratory facilities located nearby or physically connected to the public health laboratory. Such facilities might have vulnerabilities that could impact the laboratory without the laboratory having any direct control over their mitigation.

**e. Critical Considerations**

- (1) Many states lack sufficient resources to ensure self-sufficiency through internal back-up systems and redundancy through regionalization.
- (2) Few states have the capacity to absorb a significant increase in screening volume for the laboratory and follow-up functions in the case of an emergency.

- (3) Because of a lack of standardized screening requirements among states, contingency newborn screening programs in those states providing screening assistance to states in need may not screen for all of the recommended conditions.
- (4) Contingency newborn screening programs may not have the medical expertise needed to follow up with infants that tested positive.

**f. Critical Assumptions**

- (1) National and/or regional back-up systems and redundancy are required to ensure continuity of newborn screening operations.
- (2) Preparations for newborn screening contingencies must occur before the need for their implementation.

**g. Mission Essential Tasks**

- Planning continuity of operations.
- Contingency planning.
- Collecting specimens.
- Transporting specimens.
- Processing specimens.
- Confirming positive test results.
- Reporting test results.
- Tracking affected displaced populations.
- Ensuring the availability of treatment and management resources.
- Educating families about newborn screening.
- Continuity of communications processes, such as Health Information Technology (HIT).
- Training newborn screening contingency respondents and stakeholders.
- Communicating newborn screening contingency plan details to partners and stakeholders.
- Coordinating the inclusion of state newborn screening contingency plans into the state's overall preparedness plan.

**h. References:**

National Security Decision Directive 47 (NSDD-47) approved by the President of the United States in July 1982.

CDC Emergency Operations Plan (2009).

Integrated Planning System (2009).

Anderson HC, Narumanchi TC, Cunningham A, Bowdish B, Thoene J. Genetic/metabolic health care during and after hurricanes Katrina and Rita. *Molecular Genetics and Metabolism*. 2006;88:3–6.

MS Watson, MY Mann, MA Lloyd-Puryear, P Rinaldo, RR, Howell, Newborn Screening: Toward a Uniform Screening Panel and System—Executive Summary. *Pediatrics*. Suppl. Am Acad Pediatrics. DOI: 10.1542/peds.2005-2633B 2006;117:296–307.

*The Newborn Screening Saves Lives Act of 2008.*

Guidelines for the Public Health Laboratory Continuity of Operations Plan, Association of Public Health laboratories (APHL).

Emergency Preparedness for Newborn Screening and Genetic Services, American College of Medical Geneticists (ACMG).

Oregon Practitioner's Manual Newborn Screening Program 8<sup>th</sup> Edition, 2008.

US Newborn Screening System Guidelines II: Follow-up of Children, Diagnosis, Management, and Evaluation, 2000.

## II. MISSION

CDC and HRSA will work with our public health newborn screening partners to assure continuity to newborn care and to develop a comprehensive and uniform system of screening infants born in the United States for all of the American College of Medical Genetics 29 recommended disorders in the event of a public health emergency, as specified in the *Newborn Screening Saves Lives Act of 2008*.

## III. EXECUTION

### a. CDC Director's Intent

Screening newborns for easily identifiable and treatable heritable diseases is an ethical imperative for our nation. State and local health department resources are often overwhelmed during a public health emergency. My intent is to use this contingency plan to provide direction and guidance to CDC organizations to help the United States government and HHS, in collaboration with State Departments of Health (or related agencies), prepare, mitigate, respond to, and recover from a public health emergency by protecting the lives of our most vulnerable citizens. By doing so, not only will we protect these lives, but we stand to gain by preventing severe or costly health consequences.

I consider the indicators of success to be the following: (1) development of a national plan to provide consistency of screening, diagnosis, follow-up and case management during a public health emergency response; and (2) ability to provide rapid assistance with the necessary resources and actions to respond to public health emergencies. As the Director, I remain wholly and fully committed to the health and well-being of our nation's newborns.

### b. HRSA Administrator's Intent

Experience with population-based newborn screening programs has shown them to be beneficial to newborns. Screening is carried out by analysis of a drop of blood, usually obtained from a heel stick or, in the case of congenital hearing loss, by audiometric analysis. Some emergency situations offer a narrow window of opportunity during which those likely to be impacted can prepare (e.g., Hurricanes Katrina and Rita in 2005) ([Anderson et al. 2006](#)), whereas others occur with no warning (e.g., earthquakes, biologic events, terrorism-related events). To ensure continuity of critical programs, emergency preparedness planning and ongoing exercising of the plans is essential. Newborn screening should be a critical element of every state's emergency preparedness plan.

The public health and medical genetics community have found that some of their programs and patients are particularly vulnerable during these situations and that the technologies of medical genetics can be of importance in mass casualty situations. To ensure the facilitation of preparedness planning, I intend to provide the resources available to HRSA, such as the State Title V maternal and child health programs, including programs for children with special health care needs, and the National Newborn Screening and Genetics Resource Center, the HRSA-funded Regional Genetic and Newborn Screening Service Collaboratives and their national coordinating center, as they are needed.

As the Administrator, I remain wholly and fully committed to the health and well-being of our nation's newborns. I agree to coordinate these efforts as appropriate with the CDC and other federal, state, and nongovernmental agencies and organizations.

### c. Concept of Operations

#### (1) General

Newborn screening is organized as a system that includes the following: screening, short-term follow-up, diagnosis, treatment and management, and evaluation and education. The newborn screening program's efficiency and effectiveness depend on the smooth integration of sample collection, laboratory testing, follow-up diagnosis, timely treatment, and tracking of outcomes. Newborn screening is a system that intersects both the public and private sectors.

For the screening component, public health laboratories play an essential role in public health and safety, including the screening of newborn infants. Although laboratories in the private sector may provide analytical services, the core activities of public health laboratories are uniquely focused on population health rather than individual health. This focus requires public health laboratories to have special analytical expertise, instrumentation, methods, and response capability not available in the private sector. Consequently, it is imperative that public health laboratories are able to continue their core population-based activities when emergency events occur that disrupt their normal operation. For the follow-up, diagnosis, management and treatment aspects of the system, the newborn screening program must have protocols that delineate roles and responsibilities for who is responsible for follow-up and what that follow-up should be.

Most sectors of government, as well as many successful corporations in the private sector, have developed plans to ensure continuity in the event of disaster or emergency. These plans are generally referred to as "Continuity of Operations Plans," or COOP. Recent experience has shown the benefit of developing COOP procedures for newborn screening in advance of an emergency. While many partners work daily to ensure the best health care is provided to newborns, it is precisely during times of disaster or emergency response that we need to work together to ensure that the most vulnerable of our population are not forgotten.

This Contingency Plan seeks to bring together the collective efforts of all newborn screening partners into a cohesive strategy to provide essential screening services during times of local or national duress. Because the processes and procedures of public health activities vary considerably within and among states in terms of their organization, structure, and operation, each state entity should develop its own specific COOP.

The magnitude and importance of this challenge demands a cooperative and collaborative effort across the entire newborn screening community, from the local to the national level. Through a variety of outreach efforts, the following have been identified as partners in the effort to ensure the success of this effort.

#### **National Partners**

- APHL (Association of Public Health Laboratories)
- AMCHP (Association of Maternal and Child Health Programs)
- CDC (Centers for Disease Control and Prevention)
- HRSA (Health Resources and Services Administration)
- NNSGRC (National Newborn Screening and Genetics Resource Center)
- NCC (National Coordinating Center for the Regional Genetic and Newborn Screening Collaboratives)
- ASTHO (Association of State and Territorial Health Officials)
- AAP (American Academy of Pediatrics)
- NACCHO (National Association of County and City Health Officials)
- ACMG ( American College of Medical Geneticists)

- State newborn screening program directors
- Patient Advocacy groups
- Manufacturers of newborn screening tests and supplies
- Regional disaster organizations
- National test methods and capabilities of all newborn screening

#### **City, County, or State Partners**

- Emergency Response Centers
- State Homeland Security Agency
- EMAC (Emergency Management Assistance Compact): national governor's interstate mutual aid compact that facilitates the sharing of resources, personnel, and equipment across state lines during times of disaster and emergency.
- Press Offices
- Public Health Departments

#### **Local Partners**

- Hospitals
- Clinics
- Physicians, nurses, and allied health practitioners
- Health professional associations
- Hospital associations
- Case Managers
- Specimen delivery systems
- Reference laboratories
- Local public health department laboratories (non-contract and contract)

### **(2) Pre-alert or Activation Responsibilities**

#### **(a) Manufacturer or supplier responsibilities.**

- Adequate forward stocking established.
- Alternate transportation plans established.
- Plan to provide equipment to alternate site(s) within a specific time frame.

#### **(b) State Health Official Responsibilities.**

- Establish an emergency preparedness plan that includes newborn screening program and its laboratory capabilities.
- Amend or establish EMAC, MOU/MOAs to include newborn screening contingency planning.
- Establish contract with partners and vendors to include newborn screening contingency planning.

Newborn screening programs vary by state because of the uniqueness of each public health department and the political environment of their respective State. As such, it is outside the scope of this plan to address state specific details for newborn screening contingency planning. However, by being proactive and having a well thought out and practiced contingency plan in place, a state can ensure a much smoother assistance process. When developing a state newborn screening contingency plan, there are several key factors to consider:

- Coordination at all levels is imperative. Consider entering into reciprocal agreements with several partner states in different geographic regions. Further consider developing a shared response, thereby easing the testing load of any one state. Consider taking advantage of existing conferences, workshops, and training to discuss NBS contingency planning.
- Redundancy is critical to ensure continuity. Do not assume anything; consider that if something can go wrong, it probably will at some point. Redundancy should be planned in-depth (multiple methods to respond to a system or component failure; a secondary response identified should the primary backup fail). Evaluate every aspect of the newborn screening program and determine what would happen if each aspect failed; if an aspect cannot be allowed to fail, develop backups.
- Communication is critical, both lateral (intrastate) and vertical (interstate) communication. A perfect plan is bound to fail if people are not aware of the details.
- Training assures that each aspect of the response network exercises their pre-coordinated responsibilities, and it affords the participants the opportunity to provide suggestions for improvement.
- Conduct drills and consider performing joint emergency drills with reciprocal agreement states. One of the benefits of these practice drills is the opportunity to examine quality assurance parameters.
- Develop a state Continuity of Operations (COOP) Plan.

Because the processes and procedures of public health activities vary considerably within and among states in terms of their organization, structure, and operation, each state entity should develop its own specific COOP.

  - The COOP provides a prearranged plan of action to ensure that all core activities are continued without delay. The COOP applies to all of the operations, infrastructure, and resources necessary to achieve the full spectrum of newborn screening and follow-up activities.
  - Refer to Section 3: Considerations for COOP Development (below) for recommended considerations regarding COOP planning.

**(c) State Public Health Laboratory Responsibilities.**

- Establish backup testing methods or plans.
- Obtain documentation that manufacturer or supplier has:
  - Adequate forward stocking established;
  - Alternate transportation plans established.
- Ensure contracts hold manufacturer or supplier responsible when materials are not delivered as scheduled, including:
  - Cost of alternate testing instruments, materials, or outsourced testing;

- Cost of staff time to implement alternate testing;
- Liability for litigation caused by delay in reporting abnormal test results.
- Increase harmonization of laboratory methods so that results are comparable between states.
- Establish interstate and regional agreements for ensuring backup of laboratory capacity.
- Establish back-up plans to ensure diagnosis and follow-up services for infants who test positive.
- Establish a public health laboratory COOP (See next section for recommended considerations when developing a COOP).

### **(3) Considerations for COOP Development for the Laboratory**

A COOP—the processes and procedures of public health activities vary considerably within and among states in terms of their organization, structure, and operation; each entity should develop its own specific COOP. A COOP for a public health laboratory should have two basic features: 1) A COOP provides a comprehensive, pre-identified list of all core testing, support activities, and supplies that must be maintained if the laboratory experiences a partial or complete operational disruption. 2) A COOP provides a prearranged plan of action to ensure that all these core activities are continued without delay.

The COOP applies to all of the operations, infrastructure, and resources necessary to continue the laboratory activities deemed essential to fulfill governmental responsibilities. The nature of the work done in the public health laboratory requires that its COOP be developed as a special part of the business continuity plan of the agency within which it operates.

The scope of the laboratory COOP should include all time-sensitive core activities of the public health laboratory, including technology and required support. The COOP should also have the capability to scale down to accommodate lesser disruptions. Specific plans of action should be developed, and groups of personnel should be identified and trained to implement these predefined actions to ensure timely recovery. Some items to consider in COOP planning include, but are not limited to, the following:

#### **On-site Operation—Short Term**

##### (1) Emergency electrical power available for:

- Specimen acquisition.
- Demographic entry or test reporting.
- Case managers.
- Instruments.
- Laboratory information management system.
- Refrigeration.
- Heating and cooling work areas.

##### (2) Maintain a 3-month supply of testing materials.

##### (3) Identify alternate water sources.

##### (4) Availability of data systems to ensure record integrity and timely transmission of test results to providers and state programs.



### **On-site Operation—Long Term**

- (1) Prioritize tests to be reported.
- (2) Identify states with same screening materials.
- (3) Identify states with similar reporting mechanisms (e.g., Web-based, fax, voice response system).

### **Off-site Operation**

- (1) Identify contacts at offsite facility.
- (2) Establish Memoranda of Understanding (MOU) with neighboring states.
- (3) Establish a plan for compensation.
- (4) Establish a plan for specimen transport.
- (5) Establish a plan for communication of abnormal tests results to submitters or specialists.
- (6) Establish a plan for communication of all test results to submitters.
- (7) Prepare for temporary relocation of staff.
  - Identify in-house staff.
  - Identify financial mechanisms for travel and housing.
- (8) Establish a plan for access, retrieval, and entry of all data into local information system after local operation reestablished.
- (9) Establish a communication plan for the development and delivery of Public Service Announcements (PSAs) to inform hospitals and the public of process changes.
- (10) Establish a plan for return to normal operations.

**(4) Deployment - To Be Published By State Authority (as required).**

### **(5) Strategic and Operation Objectives**

At best, newborn screening during a contingency situation will be a challenging endeavor. To properly prepare for contingency operations, it is necessary to describe beforehand what actions are required to ensure newborn screening can be accomplished. Each strategic objective, as provided in the Act, requires supporting actions to be accomplished. The following outlines the major supporting actions that each public health official should consider when planning and preparing for newborn screening contingency operations. The responsible entities for each action are outlined in [Appendix B: Responsibilities Matrix](#). Each state should also ensure that their newborn screening contingency plan is integrated into the overall state preparedness plan.

#### **(a) Responsibilities by Strategic Objective.**

Each strategic objective is supported by specific operational objectives, which are further supported by specific activities. Each activity has a party or entity that is responsible for ensuring proper implementation of that supporting activity. Further, it is incumbent upon each responsible entity to develop and maintain specific Standard Operating Procedures (SOPs) that detail how each activity is executed within their jurisdiction or scope of

responsibility. SOPs generally detail who, what, why, when, where, and how and should be exercised and reviewed or updated on a regular basis to ensure they reflect the current method in which the entity operates.

**Strategic Objective 1—Specimens are collected and transported.**

- a Operational Objective: NSQAP-certified blood spot collection cards with the ability to capture appropriate demographics that also allow follow-up are available for use by any U.S. newborn screening program.

Supporting Activities

- Notify a repository of blood spot collection cards for use by any U.S. newborn screening program.
- Facilitate redistribution of locally available cards until supplies are exhausted.
- Activate national repository to deliver cards in anticipation of local supplies being depleted.
- Facilitate distribution of cards to jurisdiction.
- Facilitate distribution of cards to collection points.

- b Operational Objective: Other materials required for blood spot collection are available.

Supporting Activities

- Ensure availability of materials required for blood spot collection, including lancets, alcohol pads, and packaging at hospitals and other potential collection sites.

- c Operational Objective: A valid, adequate, or satisfactory blood spot specimen has been collected from all newborns before leaving the birthing facility.

Supporting Activities

- Train medical professionals that may be involved in dried blood spot collection.
- Collect appropriate specimens.
- Record accurate demographics (to allow complete screening, including follow-up).
- Maintain a log of all dried blood spot specimens collected or refused at the collection site.
- Forward completed and dried specimen to shipping location.

**Strategic Objective 2—Specimens are shipped to the designated newborn screening laboratory site.**

- d Operational Objective: Specimens are shipped to the appropriate laboratory within 24 hours of collection.

Supporting Activities

- Assess the situation and the operational status of laboratories and transport system.
- Make a decision about which laboratory to use.

- Ship to primary laboratory, if available; ship to secondary or tertiary laboratories when necessary.
  - Notify courier of any special pick-up or delivery issues (e.g., timing, location).
- e* Operational Objective: Specimens en route to potentially impacted laboratories are redirected to alternate laboratories.

Supporting Activities

- Notify courier of any special pick-up or delivery issues.
  - Contact transport system provider and execute change of address.
- f* Operational Objective: Missing specimens (including those not shipped) are recognized, and a new specimen is obtained.

Supporting Activities

- Identify missing specimens.
- Locate the baby.
- Collect a second specimen.
- Use public service announcements (PSAs) to aid in advising parents of babies affected by the incident.

**Strategic Objective 3—Specimens are processed.**

- g* Operational Objective: Situation is assessed.

Supporting Activities

- Assess facilities, supplies, utilities, staff, informatics, supply chain, transport systems, safety issues or working environment, and communication systems.
- Assess potential duration of interruption of lab capacity or service.
- Document assessment.

- h* Operational Objective: Integrity of specimens and records are secured.

Supporting Activities

- Evaluate potential risk to specimens and records.
- Take appropriate corrective actions to ensure integrity of specimens and records.
- Make a record of damaged or compromised specimens and records.

- i* Operational Objective: Repairs are made as indicated, if possible, to preserve or restore capacity.

Supporting Activities

- Contact vendors, tech support, facilities, and maintenance to determine if emergency repair support is available.
- Estimate time required to complete repairs.
- Initiate repairs, as feasible.

- Maintain a record of any repairs made.

*j* Operational Objective: Decision is made regarding whether additional or alternative capacity is needed.

Supporting Activities

- Make a timely judgment whether existing resources are sufficient or if a back-up lab is needed.
- Identify the appropriate resources that are needed to achieve capacity.

*k* Operational Objective: If additional capacity is needed, seek assistance or activate back-up plan.

Supporting Activities

- Contact APHL and NNSGRC.
- Decide whether to activate EMAC.
- Identify and contact back-up lab.
- Establish disorder panel needs.
- Identify and address or resolve major algorithm, IT, and methodological or protocol differences.
- Ensure that the back-up laboratory is CLIA approved and participates in the CDC NSQAP.

*l* Operational Objective: Appropriate internal and external stakeholders (including personnel) are notified.

Supporting Activities

- Notify personnel according to internal procedures.
- Notify external stakeholders, including the public, as needed.

*m* Operational Objective: A record of all DBS specimens sent to and received by the back-up laboratory is maintained.

Supporting Activities

- All entities submitting specimens keep a log of specimens submitted.
- All entities receiving specimens keep a log of specimens received.
- When possible and as feasible, compare records of transported specimens.
- Identify missing specimens.

*n* Operational Objective: A system at the back-up lab for managing external specimens from routine collections is activated.

Supporting Activities

- Back-up laboratories sort external specimens.

*o* Operational Objective: Specimens are analyzed and results are reported.

Supporting Activities

- Analyze specimens.

- Report results to submitters.
- Report the positive results to the follow-up system.
- Unsatisfactory and out of range are reported to appropriate follow-up system.
- Request second specimen, if needed.

**Strategic Objective 4—Screening results are reported to physicians and families.**

p Operational Objective: Communication lines are established and utilized between screening laboratory and newborn screening follow-up coordinator.

Supporting Activities

- Assess options for communication between laboratories and newborn screening follow-up coordinator.
- Formulate communication strategy.
- Implement strategies for communication.

q Operational Objective: Communication lines are established and utilized between the newborn screening program and physician or health care provider.

Supporting Activities

- Determine if newborn screening card submitter or physician of record is available.
- Identify alternative provider to report results, if needed.
- Report result to submitter or physician of record or alternative provider.
- Health care provider indicates to newborn screening coordinator that infant is in care.

r Operational Objective: If appropriate health care provider is not available, communication between newborn screening program and families will occur (when allowable by law).

Supporting Activities

- Locate family.
- Inform family of newborn screening results and need for additional care.
- Link family to health care.

s Operational Objective: All screening specimens are tracked.

Supporting Activities

- Develop a registry of specimens collected.
- Record all positive, unsatisfactory, and negative results in registry.
- Resolve all open newborn screening follow-up cases.

t Operational Objective: Infants who are not screened are identified.

Supporting Activities

- Match screening records with birth records to identify infants not screened.

- Contact families of infants who did not receive newborn screening.

**Strategic Objective 5—Positive diagnostic screening results are confirmed.**

u Operational Objective: Appropriate diagnostic testing occurs in a timely way.

Supporting Activities

- Physician of record consults with appropriate sub specialist.
- Identify indicated diagnostic test(s) and laboratories.
- Collect and send samples to laboratories.
- Report diagnostic test results to appropriate health care professionals, sub specialists, or sample submitters.

v Operational Objective: Diagnosis is established.

- Health care provider and sub specialist confer regarding diagnostic test results and establish diagnosis, as appropriate.
- Identify and conduct additional diagnostic evaluations, as appropriate.
- Communicate results to family.

w Operational Objective: Diagnostic testing is tracked.

- Notify NBS program (follow-up coordinator) of results and diagnosis.

**Strategic Objective 6—Availability of treatment and management resources is ensured.**

x Operational Objective: Appropriate treatment and services are identified for infants with diagnosis.

Supporting Activities

- Appropriate health care provider and sub specialist confer and discuss treatment recommendations and services and discuss with family.
- Provide acute or urgent care, if needed.
- Establish a medical home.

y Operational Objective: Infants with diagnoses receive appropriate multidisciplinary services through an established medical home.

Supporting Activities

- Initiate chronic condition management.
- Initiate co-management between health care provider and sub specialists.
- Refer to community-based organization(s).
- Develop a treatment plan.
- Facilitate access to counseling and social services.
- Facilitate access to medical foods, pharmaceuticals, and devices.
- Establish reimbursement mechanisms for services.

**Strategic Objective 7—Families are educated about newborn screening.**

z Operational Objective: Families of newborns know about the need for newborn screening.

Supporting Activities

- Identify pregnant women and families with newly born babies.
- Deliver information about newborn screening at the time the specimen is obtained.
- Ensure families understand the information.

aa Operational Objective: Families with newborns who are screened know how to obtain newborn screening results.

Supporting Actions

- Provide families with a contact to screening results.
- Educate families about how to use the link.

bb Operational Objective: Families know what to do in response to newborn screening results.

- Assist families with appropriate course of action.
- Provide families information about access to care.

**Strategic Objective 8—Carry out other activities determined appropriate by the HHS Secretary.**

cc Operational Objective: Preparedness issues are identified and addressed for NBS systems.

Supporting Activities

- Establish and maintain a national blood spot collection card repository communication strategy.
- Establish contingency plans for transfer of care (for affected individuals) from one health care system to another.
- Educate the families about the need for individualized emergency response plans.
- Develop preparedness plans for all components of the NBS program or system.
- Search the NBS contingency plan for instructions to "activate" various mechanisms, and make sure those mechanisms have already been established and are in place.
- Drill or practice the NBS contingency plan.
- Establish communications with local or state EMAC (i.e., each NBS program should establish these communication channels).
- Assess the NBS emergency operations plans that states have developed, and maintain an electronic library of such documents.
- Develop the mechanism or ability to assist with information, data, or results management among states for NBS systems.

- Establish relationships (among jurisdictions) related to mutual aid for NBS systems.

dd Operational Objective: Implementation, maintenance, and validation of the NBS contingency plan are performed by HHS.

**(6) Demobilization.** Procedures for standing down the plan should be developed and issues by appropriate state authority (as required).

## **b. Key HHS Roles and Responsibilities**

### *National Disaster Medical Service (NDMS)*

The NDMS operates out of the Department of Health and Human Services (HHS). The NDMS is supplemented by state and local medical resources during disasters or major medical emergencies. Medical response is led by HHS, which coordinates the Disaster Medical Assistance Teams that are groups of intermittent federal employees who volunteer to be on a designated team for NDMS. Teams of 35 with a range of health and medical skills are typically deployed. Federalization of the program allows important issues, such as licensure and certification, liability, compensation, and coverage under the Uniformed Services Employment and Reemployment Rights Act (USERRA) that addresses issues of leave from employment and reemployment.

As it relates to newborn screening and genetics patients, there are two pediatric teams in NDMS. They are primarily generalist pediatricians with limited experience in the management of many of these patients.

### *Centers for Disease Control and Prevention (CDC)*

The Office of Public Health Preparedness and Response (OPHPR) within CDC has primary oversight and responsibility for all programs that comprise CDC's terrorism preparedness and emergency response portfolio. Through an all-hazards approach to preparedness-focusing on threats from natural, biological, chemical, nuclear, and radiological events- OPHPR helps the nation prepare for and respond to urgent threats to the public's health. OPHPR carries out its mission by emphasizing accountability through performance, progress through public health science, and collaboration through partnerships. CDC also supports a Clinician Outreach and Communication Activity (COCA) that establishes partnerships with national clinician organizations to communicate information about emergency and disaster events.

CDC takes an active role in quality assurance programs for state newborn screening programs and works with the Association of Public Health Laboratories (APHL) in that regard. CDC also provides genetic expertise to states. The key elements in this effort are the National Center for Environmental Health (NCEH) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

### *Health Resources and Services Administration (HRSA)*

HRSA's Maternal and Child Health Bureau (MCHB) oversees the Title V Maternal and Child Health Services Block Grant, which includes State Formula Block Grants, Special Projects of Regional and National Significance grants and Community Integrated Service Systems grants. The largest portion of Title V goes to the states to meet critical challenges in maternal and child health, including:

- Significantly reducing infant mortality and the incidence of handicapping conditions.
- Providing and ensuring access to comprehensive care for women.



- Promoting the health of children by providing preventive and primary care services.
- Increasing the number of children who receive health assessments, diagnostic and treatment services.
- Providing family-centered, community-based, coordinated care for children with special health care needs.

In addition, HRSA/MCHB funds the National Newborn Screening and Genetics Resource Center, and a national system of Regional Genetic and Newborn Screening Service Collaboratives with an associated national coordinating center to improve access to specialty health care services within local communities and to improve the integration of public health, primary care providers, and specialists.

### **c. Common Roles and Responsibilities**

Public health officials are subject to a host of laws and regulations. The following represents roles and responsibilities that should apply across a cross section of all newborn screening partners.

- (1) Establish policies and procedures to ensure continuous performance of critical testing and support activities; and ensure sufficient stock of critical supplies;
- (2) Define the requirements, then identify and prearrange for assistance from alternate states and laboratories, if needed;
- (3) Ensure safety of all laboratory employees and visitors;
- (4) Provide communication and direction to stakeholders;
- (5) Minimize the loss of assets, resources, critical records, and data;
- (6) Reduce or mitigate disruptions to the program's operation;
- (7) Build infrastructure to support a timely recovery;
- (8) Manage effectively the immediate response to the emergency;
- (9) Provide prospective information and education for employees and stakeholders regarding roles and responsibilities during an emergency;
- (10) Maintain, exercise, or audit the COOP at least annually.

### **d. Specific Roles and Responsibilities (Refer to Appendix [B: Responsibilities Matrix](#)).**

#### **e. State and Local Coordination**

A systems approach recognizes the complexity and the multitude of stakeholders involved in newborn screening programs, including the following: affected infants, children, adults, their families, practitioners, birthing facilities, mail and courier groups, treatment centers, schools, public health officials, legislators, the public, and the importance of effective communication among them. A systems approach also recognizes the great responsibility these programs have to identify affected infants in time to prevent damage and to ensure a seamless coordination of the efforts of many people. It is recognized that appropriate treatment must be available to every affected infant through adulthood and that long-term follow-up is necessary, regardless of geographic location.

The overall goal of newborn screening programs is to improve the quality of life of babies through early diagnosis and treatment. Time is a very important element in this process. The cooperation and timely action by the parents and the medical care provider will help reach the goal of saving babies.

- (1) Newborn screening consists of the following five parts:
  - Screening— testing of newborns;

- Follow-up— rapid location, follow-up, and referral of the screen-positive infant;
  - Diagnosis— evaluation of the infant with a positive screening test to make a definitive diagnosis or exclude the disorder;
  - Management— rapid planning and implementation of long-term therapy;
  - Evaluation—validation of testing procedures; assessment of the efficiency of follow-up and intervention; and assessment of the benefit to the patient, family, and society.
- (2) Newborn screening needs to be done at least 24 hours after birth and before the baby is 5 days of age. Before the baby leaves the hospital, a few drops of blood should be taken, preferably from the baby’s heel. The blood sample should then be sent to the newborn screening laboratory. If the baby is not born in a hospital, the midwife, doctor, or local health department should help to collect the blood sample before the baby reaches 5 days of age.
- (3) It is incumbent on state authorities to coordinate the various aspects required to ensure continuity of newborn screening, including MOU/MOAs, regional compacts, EMAC, and COOP.
- (4) To identify alternative laboratories, for outsourcing or relocating, many questions need to be considered. Examples include the following questions:
- What core functions need to be transferred to the alternate laboratory?
  - What are the test volumes that will need to be accommodated?
  - Is the alternative laboratory’s capacity for the function sufficient?
  - What resources are needed to conduct the core functions transferred?
  - Will the alternative laboratory receive specimens or samples directly?
  - Will the alternative laboratory retain or return the tested specimens?
  - What test methods will the alternative laboratory use?
  - How will the test results be reported (e.g., electronically, telephone, paper)?
  - What will be expected turn-around times for acquiring laboratory results?
  - How will the specimens or samples be transported to the laboratory?
  - Does the alternative laboratory have the required certifications?
  - Does the alternative laboratory have the necessary security?
  - Is the alternative laboratory a member of the Laboratory Response Network (LRN) and/or registered with the Select Agent Program?
  - Can chain-of-custody of samples or specimens be maintained?
  - Are there liability issues to address?
  - Are there any risks to using a particular alternative laboratory?
  - What are the advantages or disadvantages of using a particular laboratory?
  - What financial arrangements will be necessary?
  - Is the availability of the alternative laboratory limited by length of time?

- f. **Non-Governmental Organizations (NGO) coordination requirements.** To Be Published, as required.
- g. **Private sector coordination requirements.** To Be Published, as required.
- h. **Key federal decisions.** To Be Published, as required.
- i. **Actions required and prohibited of the federal government.** To Be Published, as required.
- j. **Director's Critical Information Requirements (DCIRs).**

The CDC Director's and HRSA Administrator's Critical Information Requirements (DCIRs) are used as criteria or triggers to determine what information should be communicated to CDC and HRSA leadership to assist in making critical decisions regarding both agencies' preparation for and response to an emergency. If one of the DCIRs is met it may trigger an increased level of awareness, increased contact with partners, event-specific planning, or initiation of and response activities. The DCIRs applicable to newborn screening include:

- (1) Report significant disruptions to state or regional newborn screening capabilities.
- (2) Report any requests for CDC or HRSA assets or assistance in coordinating newborn screening in the event of a public health emergency.
- (3) Report any significant disruptions in the availability of newborn screening treatment and management resources.
- (4) Report any requests made by the HHS Secretary regarding execution of newborn screening activities.
- (5) Report any abnormal trends from newborn screening results.

#### **IV. ADMINISTRATION, RESOURCES AND FUNDING**

- a. **Administration.** To Be Published, as required.
- b. **Resources**
  - (1) **Concept of logistics support.** To Be Published, as required.
    - **Logistics management.** To Be Published, as required.
    - **Prepositioned resources.** To Be Published, as required.
- c. **Funding**

Financing of back-up services is an additional area to consider in the development of emergency preparedness contingency plans. Costs must be tracked, purchasing requirements met, invoicing systems agreed to, and mechanisms agreed on for payment for services. Methods through which back-up diagnostic and clinical service providers can be reimbursed also should be considered during the development of a state contingency plan.

#### **V. OVERSIGHT, COORDINATION, AND COMMUNICATIONS**

- a. **Oversight**

*Legal issues:* Numerous legal issues have to be considered in developing a contingency plan for newborn screening emergency preparedness. The magnitude of the disaster may impact whether all resources or capabilities can be managed locally or whether additional resources or capabilities are required that are not managed locally (e.g. resources and capabilities provided via EMAC).

Memos of understanding with those involved in providing backup services, interstate compacts, and other agreements can cover issues, such as medical licensing, which state's rules cover return and storage of materials, malpractice and liability of responders, and other factors.

**b. Coordination**

*Pre-event Planning and Exercises:* Contingency plans are only as good as the preparation to employ them. They should be reviewed periodically and, where possible, they should be practiced. Areas for improvement can be identified through exercises or experience gained through prior emergencies. Given the wide range of potential types of emergency situations and variability in forewarning, redundancy becomes increasingly important. Everyone with an interest in newborn screening programs, including patients, providers and their institutions, and emergency responders must assume overlapping responsibility for the continuation of all aspects of the program.

Periodic conferences that discuss details of newborn screening contingency plans, MOU/MOAs, are highly beneficial tools to maintain attention on these plans and allow for periodic updates as needs or situations warrant.

**c. Communications.** Effective newborn screening communications support involves addressing issues that arise during the course of normal operations and planning, as well as COOP. Recommendations for consideration and inclusion include the following:

(1) Define or establish a newborn screening emergency response system.

- (a) Establish an incident command system.
- (b) Define the chain of command.
- (c) Identify a record keeper for events.
- (d) Identify contacts and establish a relationship with:
  - Manufacturer or supplier;
  - APHL;
  - AMCHP;
  - ASTHO;
  - Other states;
  - Alternate laboratories;
  - Other partners and stakeholders.
- (e) Define a call-back system for in-house staff, partners, and stakeholders.
- (f) Test the system at least annually.
- (g) Review and update the system at least semiannually.
- (h) Modes of communication:
  - 1 Telephones with e-mail.
    - Landlines
    - Cell
    - Satellite
  - 2 Trunked communication system— computer controlled radio system.

3 Courier.

4 Alternate communication systems.

(2) *Communication in an emergency situation.* Communication is a critical need during emergency situations. State programs should take the lead in raising public awareness regarding newborn screening. Specimen tracking, referral coordination, and diagnostic confirmation are just some of the critical communications tasks that may become more complex to accomplish efficiently and effectively in an emergency situation. Patients may be seeking services and provider groups may be attempting to reconnect among themselves and other providers. Websites at multiple locations with critical information about program plans, and contact information for the various entities involved in emergency preparedness can be useful, and the development of centralized communication hotlines also can be useful. Among the options available for direct communication include:

- (a) Cellular telephones, if operational;
- (b) Voice-Over-Internet Protocols (VOIP) allows phones and computers to communicate;
- (c) Video conferencing equipment allows for communication and sharing of images and files, as well as the direct delivery of care through tele-health systems;
- (d) Satellite-based communication systems provide a valuable back-up means of ensuring communication;

Regardless of the communication strategy chosen, mechanisms for maintaining their power source should be available.

(3) *Communications 'Go Pack'.* In the event of an emergency that requires the implementation of the COOP, access to the public health laboratory building may be impossible. Important data located on the laboratory's servers may not be available for hours or days. Therefore, it is essential that any critical data needed for activation of the COOP be stored at an off-site location for ready access. To store these data, a "go-pack" should be prepared and kept in an easily accessible location. This pack should contain all of the necessary documents to activate and implement the COOP. In addition to a hard copy of the COOP, it should also be stored electronically on a USB flash drive. In addition to the Plan, the pack should contain the necessary contact information for all of the staff, clients, couriers, alternate laboratories, vendors, and emergency management personnel, among others. It should also have key contact information for APHL, CDC, and HRSA, as well as any relevant standard operating procedures needed to carry out COOP activities. To ensure availability, this information may also be stored on a secure external Website.

(4) *Implementation of the COOP.* Implementation requires immediate activation of the COOP "notification team" to contact all key individuals and groups to provide them with essential information and guidance. Among those that need to be contacted by the notification team are the following:

- All required response teams.
- Agency's Health Officer.
- State epidemiologist.
- State Title V MCH Director.
- All impacted agency leaders.
- All laboratory staff.
- All newborn screening program staff.

- All impacted submitters of samples and specimens.
- All alternative laboratories and newborn screening programs that may be required to assume core functions.

**Appendices:**

- A. Funding Issues (To Be Published, as required)**
- B. Responsibilities Matrix**
- C. Model Memorandum of Understanding**
- D. Newborn Screening Program Response Network (To Be Published, as required)**
- E. Nongovernmental Organizations (NGOs) (To Be Published, as required)**
- F. Public Affairs (To Be Published, as required)**
- G. Acronyms**

**APPENDIX B - RESPONSIBILITIES MATRIX**



Strategic Objective #1	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Specimens are collected and transported.	1. NSQAP-certified blood spot collection cards with the ability to capture appropriate demographics that also allow follow-up are available for use by any U.S. newborn screening program.	<ol style="list-style-type: none"> <li>1. Notify a repository of blood spot collection cards for use by any U.S. newborn screening program.</li> <li>2. Facilitate redistribution of locally available cards until supplies are exhausted.</li> <li>3. Activate national repository to deliver cards in anticipation of local supplies being depleted.</li> <li>4. Facilitate distribution of cards to jurisdiction.</li> <li>5. Facilitate distribution of cards to collection points.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening program, in accordance with jurisdictional rules; jurisdictional health official or designee.</li> <li>2. Newborn screening program.</li> <li>3. Newborn screening program, in accordance with jurisdictional rules; jurisdictional health official or designee.</li> <li>4. Newborn screening program; APHL.</li> <li>5. Newborn screening program; state hospital preparedness coordinator.</li> </ol>
	2. Other materials required for blood spot collection are available.	<ol style="list-style-type: none"> <li>1. Ensure availability at hospitals and other potential collection sites of materials required for blood spot collection including lancets, alcohol pads, and packaging.</li> </ol>	State Health Official; Newborn Screening Program Director; State Hospital Preparedness Director	<ol style="list-style-type: none"> <li>1. Hospitals and other potential collection sites and the state hospital preparedness coordinator.</li> </ol>
	3. A valid, adequate, or satisfactory blood spot specimen has been collected from all newborns before leaving the birthing facility.	<ol style="list-style-type: none"> <li>1. Train medical professionals who may be involved in dried blood spot (DBS) collection.</li> <li>2. Collect appropriate specimens.</li> <li>3. Record accurate demographics (to allow complete screening, including follow-up).</li> <li>4. Maintain a log at the collection site of all DBS specimens collected or refused.</li> <li>5. Forward completed and dried specimen to shipping location.</li> </ol>	State Health Official; Newborn Screening Program Director; State Hospital Preparedness Director	<ol style="list-style-type: none"> <li>1. Hospitals and other potential collection sites.</li> <li>2. Hospitals and other potential collection sites.</li> <li>3. Hospitals and other potential collection sites.</li> <li>4. Hospital and other potential collection sites.</li> <li>5. Hospital and other potential collection sites.</li> </ol>



Strategic Objective #2	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Specimens are shipped to the designated newborn screening laboratory site.	1. Specimens are shipped to the appropriate laboratory within 24 hours of collection.	<ol style="list-style-type: none"> <li>1. Assess situation and the operational status of laboratories and transport system.</li> <li>2. Make decision about which laboratory to use.</li> <li>3. Ship to primary laboratory, if available; ship to secondary or tertiary laboratories, when necessary.</li> <li>4. Notify courier of any special pick-up or delivery issues (e.g., timing, location.)</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening programs; hospital preparedness coordinator.</li> <li>2. Jurisdictional health official or designee; newborn screening programs.</li> <li>3. Hospital and other potential collection facilities.</li> <li>4. Newborn screening program.</li> </ol>
	2. Specimens en route to potentially impacted labs are redirected to alternate labs.	<ol style="list-style-type: none"> <li>1. Notify courier of any special pick-up or delivery issues.</li> <li>2. Contact transport system provider and execute change of address.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening programs.</li> <li>2. Newborn screening programs; potentially impacted laboratory.</li> </ol>
	3. Missing specimens (including those not shipped) are recognized, and a new specimen is obtained.	<ol style="list-style-type: none"> <li>1. Identify missing specimens.</li> <li>2. Locate the baby.</li> <li>3. Collect a second specimen.</li> <li>4. Utilize Public Service Announcements (PSAs) to aid in advising parents of babies affected by the incident.</li> </ol>	State Health Official; Newborn Screening Program Director; State Hospital Preparedness Director	<ol style="list-style-type: none"> <li>1. Hospitals and other potential collection facilities, newborn screening programs, health care provider, parents.</li> <li>2. Hospitals and other potential collection facilities, newborn screening programs, health care provider, parents.</li> <li>3. Hospitals and other potential collection facilities.</li> <li>4. Newborn screening program (as part of the Joint Information System).</li> </ol>

Strategic Objective #3	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Specimens are processed.	1. Situation is assessed.	<ol style="list-style-type: none"> <li>1. Assess facilities, supplies, utilities, staff, informatics, supply chain, transport systems, safety issues or working environment, and communication systems.</li> <li>2. Assess potential duration of interruption of lab capacity or service.</li> <li>3. Document assessment.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening lab.</li> <li>2. Newborn screening lab.</li> <li>3. Newborn screening lab.</li> </ol>
	2. Integrity of specimens and records are secured.	<ol style="list-style-type: none"> <li>1. Evaluate potential risk to specimens and records.</li> <li>2. Take appropriate corrective actions to ensure integrity of specimens and records.</li> <li>3. Make a record of damaged or compromised specimens and records.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening lab.</li> <li>2. Newborn screening lab and newborn screening program.</li> <li>3. Newborn screening lab and newborn screening program.</li> </ol>
	3. Repairs are made as indicated, if possible, to preserve or restore capacity.	<ol style="list-style-type: none"> <li>1. Contact vendors, tech support, facilities, maintenance to determine if emergency repair support is available.</li> <li>2. Estimate time required to complete repairs.</li> <li>3. Initiate repairs, as feasible</li> <li>4. Maintain a record of any repairs made.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening lab.</li> <li>2. Newborn screening lab.</li> <li>3. Newborn screening lab.</li> <li>4. Newborn screening lab.</li> </ol>
	4. Decision is made regarding whether additional or alternative capacity is needed.	<ol style="list-style-type: none"> <li>1. Make a timely judgment whether existing resources are sufficient or if a back-up lab is needed.</li> <li>2. Identify the appropriate resources that are needed to achieve capacity.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening lab and newborn screening program.</li> <li>2. Newborn screening lab and newborn screening program.</li> </ol>
	5. If additional capacity is needed, seek assistance or activate back-up plan.	<ol style="list-style-type: none"> <li>1. Contact APHL and NNSGRC.</li> <li>2. Decide whether to activate EMAC.</li> <li>3. Identify and contact back-up lab.</li> <li>4. Establish disorder panel needs.</li> <li>5. Identify and address or resolve major algorithm, IT, and methodological or protocol differences.</li> <li>6. Ensure that the back-up laboratory is CLIA-approved and participates in the CDC NSQAP.</li> </ol>	State Health Official; Newborn Screening Program Director	<ol style="list-style-type: none"> <li>1. Newborn screening lab.</li> <li>2. Newborn screening lab and newborn screening program or jurisdictional public health official or designee.</li> <li>3. Newborn screening lab.</li> <li>4. Newborn screening lab and newborn screening program or back-up lab.</li> <li>5. Newborn screening lab and newborn screening program or back-up lab.</li> <li>6. Newborn screening lab and back-up lab.</li> </ol>

Strategic Objective #3 (continued)	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
	6. Appropriate internal and external stakeholders (including personnel) are notified.	1. Notify personnel according to internal procedures. 2. Notify external stakeholders, including the public as needed.	State Health Official; Newborn Screening Program Director	1. Newborn screening lab and newborn screening program. 2. Newborn screening lab and newborn screening program or back-up lab.
	7. A record of all dried blood spot (DBS) specimens sent to and received by the back-up lab is maintained.	1. All entities submitting specimens keep a log of specimens submitted. 2. All entities receiving specimens keep a log of specimens received. 3. When possible or as feasible, compare records of transported specimens. 4. Identify missing specimens.	State Health Official; Newborn Screening Program Director	1. Submitting entities. 2. Back-up labs. 3. Newborn screening program and newborn screening lab or back-up lab. 4. Newborn screening lab or back-up lab.
	8. A system at the back-up lab for managing external specimens from routine collections is activated.	1. Back-up labs sort external specimens.	State Health Official; Newborn Screening Program Director	1. Back-up labs.
	9. Specimens are analyzed and results are reported.	1. Analyze specimens. 2. Report results to submitters. 3. Report the positive results to the follow-up system. 4. Unsatisfactory and out of range are reported to appropriate follow-up system. 5. Request second specimen, if needed.	State Health Official; Newborn Screening Program Director	1. Back-up labs. 2. Back-up lab; newborn screening program. 3. Back-up lab; newborn screening program. 4. Back-up lab; newborn screening program. 5. Back-up lab; follow-up program; newborn screening program.

Strategic Objective #4	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Screening results are reported to physicians and families.	1. Communication lines are established and utilized between screening lab and the newborn screening follow-up coordinator.	1. Assess options for communication between labs and the newborn screening follow-up coordinator. 2. Formulate communication strategy. 3. Implement strategies for communication.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. Public Health Emergency Management, newborn screening program. 2. Public Health Emergency Management, newborn screening program. 3. Public Health Emergency Management, newborn screening program.
	2. Communication lines are established and utilized between the newborn screening program and the physician or health care provider.	1. Determine if newborn screening card submitter or physician of record is available. 2. Identify alternative provider to report results, if needed. 3. Report result to submitter, physician of record, or alternative provider. 4. Health care provider indicates to newborn screening coordinator that infant is in care.	State Health Official; Newborn Screening Program Director State Title V MCH program	1. newborn screening follow-up coordinator 2. newborn screening follow-up coordinator 3. newborn screening follow-up coordinator 4. Appropriate physician of record (POR) and newborn screening follow-up coordinator
	3. If appropriate health care provider is not available, communication between newborn screening program and families will occur (when allowable by law).	1. Locate family. 2. Inform family of newborn screening results and need for additional care. 3. Link family to health care.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. Newborn screening follow-up coordinator. 2. Newborn screening follow-up coordinator. 3. Newborn screening follow-up coordinator.
	4. All screening specimens are tracked.	1. Develop a registry of specimens collected. 2. Record all positive, unsatisfactory, and negative results in registry. 3. Resolve all open newborn screening follow-up cases.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. Newborn screening follow-up coordinator. 2. Newborn screening follow-up coordinator. 3. Newborn screening follow-up coordinator.
	5. Infants who are not screened are identified.	1. Match screening records with birth records to identify infants not screened. 2. Contact families of infants who did not receive newborn screening.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. Newborn screening program and Vital Records. 2. Newborn screening follow-up coordinator.

Strategic Objective #5	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Diagnostic confirmation of positive screening results.	1. Appropriate diagnostic testing occurs in a timely way.	1. Physician of Record (POR) consults with appropriate sub specialist (SS). 2. Identify indicated diagnostic test(s) or lab(s). 3. Collect and send samples to lab. 4. Report diagnostic test results to appropriate health care professionals or SS or submitter.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. POR and SS. 2. SS 3. Appropriate HCP or SS. 4. Diagnostic lab.
	2. Diagnosis is established.	1. Health care provider (HCP) and sub specialist confer about diagnostic test results and establish diagnosis, as appropriate. 2. Additional diagnostic evaluations are identified and conducted, as appropriate. 3. Communicate results to family.	State Health Official; Newborn Screening Program Director State Title V MCH program.	1. AHCP, submitter, or SS. 2. AHCP, SS 3. AHCP, SS
	3. Diagnostic testing is tracked.	1. Notify newborn screening program (follow-up coordinator) of results and diagnosis.	State Title V MCH program.	1. AHCP, submitter, or SS.

Strategic Objective #6	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Availability of treatment and management resources is ensured.	1. Appropriate treatment and services are identified for infants with diagnosis.	<ol style="list-style-type: none"> <li>1. Appropriate health care provider and SS confer and discuss appropriate treatment recommendations and services with family.</li> <li>2. Provide acute or urgent care, if needed.</li> <li>3. Establish a medical home.</li> </ol>	State Health Official; Newborn Screening Program Director State Title V MCH program.	<ol style="list-style-type: none"> <li>1. AHCP, SS, and family.</li> <li>2. AHCP, SS, and family.</li> <li>3. AHCP, SS, and family.</li> </ol>
	2. Infants with diagnosis receive appropriate multidisciplinary services through an established medical home.	<ol style="list-style-type: none"> <li>1. Initiate chronic condition management.</li> <li>2. Initiate co-management between health care provider and SS.</li> <li>3. Referral to community-based organizations.</li> <li>4. Develop a treatment plan.</li> <li>5. Facilitate access to counseling and social services.</li> <li>6. Facilitate access to medical foods, pharmaceuticals, and devices.</li> <li>7. Establish reimbursement mechanisms for services.</li> </ol>	State Health Official; Newborn Screening Program Director State Title V MCH program,	<ol style="list-style-type: none"> <li>1. AHCP, SS, and family.</li> <li>2. AHCP, SS, and family.</li> <li>3. AHCP, SS, and family.</li> <li>4. AHCP, SS, and family.</li> <li>5. AHCP, SS, and family.</li> <li>6. SS, ACHP, local pharmacies, medical food manufacturers, and NGOs.</li> <li>7. State Title V MCH and FEMA.</li> </ol>

Strategic Objective #7	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (Local)
Families are educated about newborn screening.	1. Families of newborns know about the need for newborn screening.	<ol style="list-style-type: none"> <li>1. Identify pregnant women and families with newly born babies.</li> <li>2. Deliver information about newborn screening at the time the specimen is obtained.</li> <li>3. Ensure families understand information.</li> </ol>	State Health Official; Newborn Screening Program Director State Title V MCH program.	<ol style="list-style-type: none"> <li>1. Jurisdictional public health authority.</li> <li>2. Birthing or screening facility.</li> <li>3. Birthing or screening facility.</li> </ol>
	2. Families with newborns who are screened know how to obtain newborn screening results and educational materials.	<ol style="list-style-type: none"> <li>1. Provide families with a contact to screening results and educational materials.</li> <li>2. Educate families about how to use the link.</li> </ol>	State Health Official; Newborn Screening Program Director State Title V MCH program.	<ol style="list-style-type: none"> <li>1. Birthing or screening facility.</li> <li>2. Birthing or screening facility.</li> </ol>
	3. Families know what to do in response to newborn screening results.	<ol style="list-style-type: none"> <li>1. Assist families with appropriate course of action.</li> <li>2. Provide families information about access to care.</li> </ol>	State Health Official; Newborn Screening Program Director State Title V MCH program.	<ol style="list-style-type: none"> <li>1. Newborn screening program or appropriate health care provider.</li> <li>2. Newborn screening program or appropriate health care provider.</li> </ol>

Strategic Objective #8	Operational Objective	Activity	Responsible Entity (State)	Responsible Entity (L
<p>Other activities determined appropriate by the HHS Secretary are carried out.</p>	<p>Preparedness issues are identified and addressed for newborn screening systems.</p> <p>Implementation, maintenance, and validation of the newborn screening contingency plan are performed by the U.S. Department of Health and Human Services (HHS).</p>	<ol style="list-style-type: none"> <li>1. Establish and maintain a national blood spot collection card repository.</li> <li>2. Establish contingency plans for transfer of care (for affected individuals) from one health care system to another.</li> <li>3. Educate the families about the need for individualized emergency response plans.</li> <li>4. Develop preparedness plans for all components of the NBS program or system.</li> <li>5. Search the NBS contingency plan for instructions to "activate" various mechanisms, and make sure those mechanisms have already been established and are in place.</li> <li>6. Drill or practice the NBS contingency plan.</li> <li>7. Establish communications with local or state EMAC (i.e., each NBS program should establish these communication channels).</li> <li>8. Assess the NBS emergency operations plans that states have developed, and maintain an electronic library of such documents.</li> <li>9. Develop the mechanism or ability to assist with information, data, or results management among states for NBS systems.</li> <li>10. Establish relationships (among jurisdictions) related to mutual aid for NBS systems.</li> </ol>		



## APPENDIX C (MODEL MOU)

**MODEL  
MEMORANDUM OF UNDERSTANDING**  
(Some states prefer Memoranda of Agreements)  
**Between**  
**State A Department of Health**  
**and**  
**State B Department of Health**

### **Purpose**

This Memorandum of Understanding (MOU) is being established between State A Department of Health and State B Department of Health to provide reciprocal coverage, to the extent facilities and materials are available, for each other in the case of natural disasters, terrorism, or other emergencies that could temporarily cause a discontinuation of laboratory services to the citizens of the state.

### **Emergency Support Services**

State A and State B agree to provide, on a temporary basis, laboratory support services to each other, and/or permit the affected laboratory's staff to work in the other's public health laboratory to perform testing in the event of a natural disaster, terrorist event, or other emergency that could close down "mission critical" functions of State A or State B.

Laboratory services provided on a "temporary basis" means no more than four (4) weeks continuous service for a single occurrence, unless the parties mutually agree in writing to extend the time period. Where appropriate, laboratory staff from the affected laboratory may be assigned to work in the public health laboratory that is designated to provide the support services. Assigned employees will comply with rules and regulations of the support laboratory.

### **Funding**

The state laboratory that is confronted with a temporary emergency caused by a disaster agrees to reimburse at a reasonable cost the laboratory providing the support services for the cost of reagents, supplies, reproduction of laboratory reports, telephone costs, and shipping and postage fees upon submission of an itemized invoice.

### **Transportation and Delivery of Specimens or Samples**

It shall be the responsibility of the state laboratory confronted with the emergency to arrange for transport of specimens or samples to the laboratory providing support services or space for laboratory testing.

### **Chain of Custody**

All samples or specimens and physical evidence received under chain of custody will be maintained under secure conditions during storage, testing, and retention of evidence until the case is resolved. Laboratory staff involved in receipt of samples or specimens, or storage and testing agrees to respond to court-ordered subpoenas related to these samples or specimens and to testify in court, if necessary. The state agency or attorney(s) who requested the subpoenas will pay for all expenses associated with court appearances. Disposal of samples or specimens and physical evidence received under chain of custody must be approved in writing by the submitter or returned to the submitter for disposal.

### **Contact Persons**

A contact person will be identified for laboratory testing in the cooperating laboratories named in this MOU to allow immediate interaction, assessment of the situation, and appropriate arrangements necessary for the unimpeded flow of services. The contact persons for each laboratory will be the Laboratory Director whose signature is on this MOU or their successor or designated representative.

### **Liability**

Nothing in this MOU will create any right of indemnification for the benefit of either party, and each party shall be responsible for its conduct as provided by law. Nothing in this MOU will be deemed to waive any immunity available to either party, including sovereign immunity.

### **Terms and Termination**

Subject to any rights of termination hereinafter set forth, this MOU shall become effective immediately upon all parties signing and shall remain valid for 12 months. This MOU may be reviewed, and it may be renewed annually.

This MOU may be terminated by either party with or without cause upon thirty (30) days advance written notice.

This MOU shall not be altered, changed, modified, or amended except by written consent of all parties to the MOU.



## APPENDIX G: ACRONYMS

ACMG	-	American College of Medical Genetics
AHCP	-	Appropriate Health Care Provider
AMCHP	-	Association of Maternal & Child Health Programs
APHL	-	Association of Public Health Laboratories
ASTHO	-	Association of State and Territorial Health Officials
CDC	-	Centers for Disease Control and Prevention
CLIA	-	Clinical Laboratory Improvement Amendments
COCA	-	Clinician Outreach and Communication Activity
COOP	-	Continuity of Operations Plan
CONOPS	-	Concept of Operations
CONPLAN	-	Contingency Plan
OPHPR	-	Office of Public Health Preparedness and Response
DBS	-	Dried Blood Spot
DCIRs	-	CDC Director's Critical Information Requirements
DOH	-	Department of Health
EMAC	-	Emergency Management Assistance Compact
FEMA	-	Federal Emergency Management Agency
NCBDD	-	National Center on Birth Defects and Developmental Disabilities
HCP	-	Health Care Provider
HIT	-	Health Information Technology
HHS	-	U.S. Department of Health and Human Services
HRSA	-	Health Resources and Services Administration
LRN	-	Laboratory Response Network
MCH	-	Maternal Child Health
MCHB	-	Maternal and Child Health Bureau
MOA	-	Memoranda of Agreement
MOU	-	Memoranda of Understanding
NBS	-	Newborn Screening
NCBDDD	-	National Center on Birth Defects and Developmental Disabilities
NCC	-	National Coordinating Center (Regional Genetic and Newborn Screening Collaboratives)
NDMS	-	National Disaster Medical Service
NGO	-	Nongovernmental Organization
NNSGRC	-	National Newborn Screening and Genetics Resource Center
NSQAP	-	CDC's Newborn Screening Quality Assurance Program
PH	-	Public Health
POR	-	Physician of Record
PSA	-	Public Service Announcement
SOP	-	Standard Operating Procedure
U.S.	-	United States of America
USERRA	-	Uniformed Services Employment and Reemployment Rights Act
VOIP	-	Voice Over Internet Protocol