Newborn Screening

Contingency Plan

Version III—November 2024

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Newborn Screening Contingency Plan Version III

November 2024

Document Revisions

Date	Revisions	Agency Revising
July 2010	Version I Original document drafted and published online at: https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/reports-recommendations/nbs-contingency-plan.pdf (Document no longer available.)	CDC, HRSA, and associated partner organizations
August 2017	Version II Added point of care screening for critical congenital heart disease and newborn hearing. Streamlined text into a usable checklist tool for emergency planners at the state and local level.	CDC, HRSA, and associated partner organizations
June 2024	Version III Defines relevant NBS system partners and their roles, clarifies the potential role of emergency management assistance compact (EMAC), and includes additional information to advise these partners on pre-event and post-event activities for a NBS emergency response.	CDC, HRSA, and associated partner organizations

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Executive Summary

A. Background

Newborn screening (NBS) is a critical system comprised of public health and medical processes that function together to identify babies with conditions that can affect their long-term health or survival. Each year, approximately 14,000 newborns out of nearly four million babies born in the United States are diagnosed with detectable and treatable conditions, including metabolic, endocrine and other genetic disorders, hearing loss, and critical congenital heart disease (CCHDs). If diagnosed timely, these conditions can be successfully managed or treated to prevent severe and often lifelong health consequences. Each state ("states" refers to both states and territories hereafter) determines the conditions and screening procedures for its screening program. However, the U.S. Department of Health and Human Services (HHS) recommends that every NBS program include those disorders listed on the Recommended Uniform Screening Panel (RUSP). The RUSP is a list of conditions adopted by the Secretary of HHS based on guidance from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). The ACHDNC provides recommendations to the Secretary of HHS about which conditions to include on the RUSP, and the Secretary then makes the final decision on whether to add, or not add, the recommended condition.

NBS typically occurs 24 to 48 hours after birth and includes the following screening tests: dried blood spot (DBS), pulse oximetry, and hearing screening. In DBS screening, a few drops of the newborn's blood are applied to a special filter paper, dried, then sent to a laboratory to test for serious health conditions. Results from DBS screening are usually available within five to seven days after birth. For pulse oximetry screening, providers use a point-of-care (POC) device to measure the level of oxygen in the newborn's blood to assess if the baby may have certain critical congenital heart disease (CCHD). Hearing screening is also performed by a provider using POC devices to check a baby's hearing. Newborns with out-of-range or positive screening results are typically referred to a qualified specialist for additional evaluation, care, and treatment, if needed.

B. The Newborn Screening Saves Lives Act of 2008 and Reauthorization Act of 2014

On April 24, 2008, *The Newborn Screening Saves Lives Act of 2008* became public law (H.R. 3825; Report No. 110-570). The Act was reauthorized in 2014 (P.L.113-240).

This law directed the Centers for Disease Control and Prevention (CDC), in consultation with the Health Resources and Services administration (HRSA) and the State Departments of Health (or related agencies), to develop a national NBS contingency plan for use by a state, region, or consortia of states to ensure continuity of critical operations in the event of a public health emergency. The development of this framework for state and local planning was required within 180 days of enactment of the legislation. The Newborn Screening Saves Lives Reauthorization Act of 2014 stipulated that the plan was to be updated as needed and at least every five years.

C. Purpose

The Newborn Screening Contingency Plan Framework (hereafter, the Framework) was developed in 2010 and revised in 2015-16 in partnership with federal, state, local, and non-governmental organizations engaged in aspects of the NBS community. The first update to the Framework included additional information on screening for hearing loss and CCHD (Version II). This second update (Version III) to the Framework further defines relevant NBS system partners and their roles, clarifies the potential role of emergency management assistance compact (EMAC), and includes additional information to advise these partners on pre-event and post-event activities for a NBS emergency response.

The intent of the Framework is to facilitate situational awareness and coordination among federal agencies and state, local, territorial, tribal, and regional efforts to maintain NBS activities during a public health emergency. This effort concerns those areas of the NBS system (specimen collection and transport, screening test, diagnosis and follow-up, treatment and management, evaluation, and education), for which the state public health agency typically assumes an oversight role.

D. Mission

CDC and HRSA will work with their public health NBS system partners to assure continuity to newborn care and to ensure that a comprehensive and uniform system of screening U.S. newborns is maintained in the event of a public health emergency, as specified in the Newborn Screening Saves Lives Reauthorization Act of 2014.

E. Mission Essential Tasks

- Development of a comprehensive continuity of operations plan to include DBS, hearing, and CCHD screening.
- Contingency planning.
- Educating families about NBS.
- Administration of hearing and CCHD screening using appropriate equipment and methodologies.
- Collection of DBS specimens.
- Transport of DBS specimens.
- Analysis of DBS specimens.
- Reporting of screening results.
- Diagnostic testing of newborns with positive or out-of-range screening results.
- Ensuring appropriate follow-up and care prior to hospital discharge (or transfer) for newborns who fail a CCHD screen or do not pass a hearing screening.
- Locating affected and potentially displaced populations.
- Ensuring the availability of treatment and management resources.
- Continuity of communications processes, such as use of Health Information Technology.

- Training of NBS system contingency respondents and partners.
- Coordinating the inclusion of state NBS contingency plans into the state's overall preparedness plan.
- Communicating NBS contingency plan details to system partners.

F. Concept of Operations

This document is intended to be used as a framework by state health agencies, laboratories, clinicians, and other organizations that are part of the NBS system in the U.S. Each organization may use the applicable sections of this framework to create their plans.

The goal of NBS programs is to improve the quality of life of newborns through early diagnosis and treatment. NBS is organized as a system that includes the following:

- **Education:** Ongoing education of the public, parents, and health professionals.
- **Screening:** Testing newborns for select disorders, CCHD, and hearing loss.
- **Follow-up** (including results reporting): Rapid location, follow-up, and referral of the newborn with positive or out-of-range result.
- **Diagnostic confirmation:** Evaluation of the newborn with a positive or out-of-range screening test to make a definitive diagnosis or exclude the disorder.
- **Short-term and long-term management**: Rapid planning for therapy, medical, or surgical intervention(s) as needed and implementation of short-term and long-term follow-up.
- **Evaluation and continuous quality improvement:** Validation and verification of testing procedures, assessment of the efficiency of follow-up and intervention, and assessment of the benefit to the patient, family, and society.

NBS typically occurs 24 to 48 hours after birth and includes the following screening tests: DBS, pulse oximetry, and hearing.

1) **DBS screening:** A heel stick should be performed at the latest 24 to 48 hours after birth and before the baby leaves the birthing facility. Collect a small blood sample on special filter paper for laboratory analysis to detect the disorders on the NBS panel of the jurisdiction where the analysis will be conducted. If the baby is not born in a hospital, the birth attendant (e.g., midwife, doctor, or health professional) should collect or assure the collection of the blood sample within 48 hours of birth and send it to the NBS laboratory.
2) **Pulse oximetry screening:** Screening to identify CCHD should be performed after 24 hours of age or prior to discharge from the birthing facility. A pulse oximeter uses light to detect the proportion of hemoglobin that is oxygenated (e.g., the amount of oxygen in the baby's blood).
3) **Hearing screening:** Screening for hearing loss should occur before the baby leaves the birthing facility. If the baby is not born in a hospital, the hearing screen should occur before one month after birth. Auditory Brainstem Response (ABR) is a test that checks the brain's response to sound. Otoacoustic Emissions (OAE) is a test that checks the inner ear response to sound. Because these tests do not rely on the baby's response behavior, the newborn being tested can be sound asleep during the screen.

Members of the NBS community have developed a Continuity of Operations Plan (COOP), which provides information for state and local partners to develop plans to ensure continuity in the event of disaster or emergency. A COOP for a NBS program and its public health laboratories should have two basic features:

1) Provide a comprehensive, pre-identified list of all core testing, support activities (including results reporting and follow-up), and supplies that must be maintained if the laboratory or birthing facility experiences a partial or complete operational disruption.
2) Provide a prearranged plan of action to ensure that all core activities are continued without delay.

G. Effective Date, Implementation, and Revisions

This Framework's effective date will be two weeks after final publication and following the signatures from the Director of CDC's National Center for Environmental Health (NCEH) and Agency for Toxic Substances and Disease Registry (ATSDR) and the HRSA Associate Administrator of the Maternal and Child Health Bureau (MCHB). The Framework will be updated and renewed on an as-needed basis, or at least every five years. 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, be subject to the same level of scrutiny as in the preparation of the initial document.

Aaron S. Bernstein, MD, MPH
Director, National Center for Environmental Health and
Agency for Toxic Substances and Disease Registry
Centers for Disease Control and Prevention

Michael D. Warren, MD, MPH, FAAP
Associate Administrator, MCHB
Health Resources and Services
Administration

H. Common Roles and Responsibilities

Federal Roles

ASPR: HHS Administration for Strategic Preparedness and Response

ASPR was created under the *Pandemic and All Hazards Preparedness Act*, and elevated to an Operating Division within HHS in 2022. ASPR's Office of Response provides oversight and guidance to the National Disaster Medical System (NDMS) and the Strategic National Stockpile (SNS). During a public health emergency that impacts the NBS system, ASPR could provide access to life-saving medicines; deploy medical/laboratory supplies and equipment from the SNS; and offer technical assistance to assist with the response. ASPR oversees the deployment of the National Disaster Medical System (NDMS). The NDMS is supplemented by state and local medical resources during disasters or major medical emergencies. During a public health

emergency impacting the NBS system, pediatric teams in NDMS can address issues related to newborns identified through NBS and specialty clinic patients. Teams from NDMS primarily consist of pediatricians, so their expertise may not extend to specific care management needs for newborns and children living with rare disorders.

NCEH: CDC National Center for Environmental Health

The Newborn Screening Quality Assurance Program (NSQAP) within NCEH provides laboratory support to NBS programs. This support involves ensuring the accuracy of NBS tests in every U.S. state and territory for conditions that are evaluated through DBS testing. NSQAP's services include proficiency testing and quality control DBS materials, development of DBS reference materials, test development and transfer, filter paper evaluation, technical training, and consultation for recent and anticipated additions to the RUSP. NSQAP also partners with the Association of Public Health Laboratories (APHL) to provide technical services and support for NBS laboratory practice, including oversight and administration of a filter paper repository for emergency use by NBS programs.

NCBDDD: CDC National Center on Birth Defects and Developmental Disabilities

NCBDDD provides support and expertise in public health surveillance and epidemiology to states and territories. NCBDDD provides funding to support the development and implementation of state-based Early Hearing Detection and Intervention (EHDI) tracking and surveillance systems, which help to ensure that newborns are screened for hearing loss and receive recommended follow-up. NCBDDD also funds several states to track major birth defects, including CCHDs, using population-based methods. States use these data to help direct birth defects prevention activities and refer children affected by birth defects to needed services.

ORR: CDC Office of Readiness and Response

The ORR has primary oversight and responsibility for all programs that comprise CDC's public health preparedness and response portfolio. ORR works with federal, state, local, tribal, and territorial partners to respond to a public health emergency. During a public health emergency impacting the NBS system, ORR will coordinate within CDC (NCEH, NCBDDD, Office of Tribal Affairs and Strategic Alliances (OTASA), and others) and can assist with the implementation of standardized emergency management structures and distribute critical messages through the public health and medical systems. For example, ORR supports a Clinician Outreach and Communication Activity, which establishes partnerships with national clinician organizations to communicate information about emergency and disaster events.

MCHB: HRSA Maternal and Child Health Bureau

HRSA's MCHB works within the public health system to address the needs of mothers, children, and their families. MCHB oversees the Title V Maternal and Child Health Services Block Grant, funding that goes to the states to meet critical challenges in maternal and child health and for monitoring systems of care. The Division of Services for Children with Special Health Needs (DSCSHN) within MCHB works to improve health and quality of life for children and youth with special health care needs, including those identified by NBS. DSCSHN supports programs and funding that directly impact NBS programs and coordinates the functions of the ACHDNC. Specifically, DSCSHN supports state newborn screening programs to 1) address state/jurisdiction-specific challenges and pursue priorities to enhance, improve, and expand their NBS System; 2) address timely collection and reporting of NBS specimens to improve early diagnosis and treatment for individuals with

heritable conditions identified through NBS; and 3) support long-term follow-up (LTFU) activities that link public health agencies, clinicians, and families in meaningful ways.

DCIRs: CDC Director's Critical Information Requirements

DCIRs are used as criteria or triggers to determine what information should to be communicated to CDC 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, and/or initiation of response activities. The DCIRs applicable to NBS include:

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

Non-Federal Responsibilities

NBS is a system cutting across governmental public health at all levels, hospitals and midwives, health plans, manufacturers, pharmacists, clinicians, advocacy organizations, couriers, and other entities. Staff members who are involved in NBS should be made aware of the following:

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

Public health officials are subject to a host of laws and regulations. The following represents the responsibilities that should apply to a cross-section of all NBS partners:

1. Establish policies and procedures to ensure continuous performance of critical testing and support activities.
2. Ensure sufficient stock of critical supplies.
3. Define requirements for continuous operations, then identify and prearrange for assistance from alternate states and laboratories, if needed.
4. Ensure the safety of all laboratory employees and visitors.
5. Provide communication and direction to partners.
6. Minimize the loss of assets, resources, critical records, and data.
7. Reduce or mitigate disruptions to the program's operation.
8. Build infrastructure to support a timely recovery.

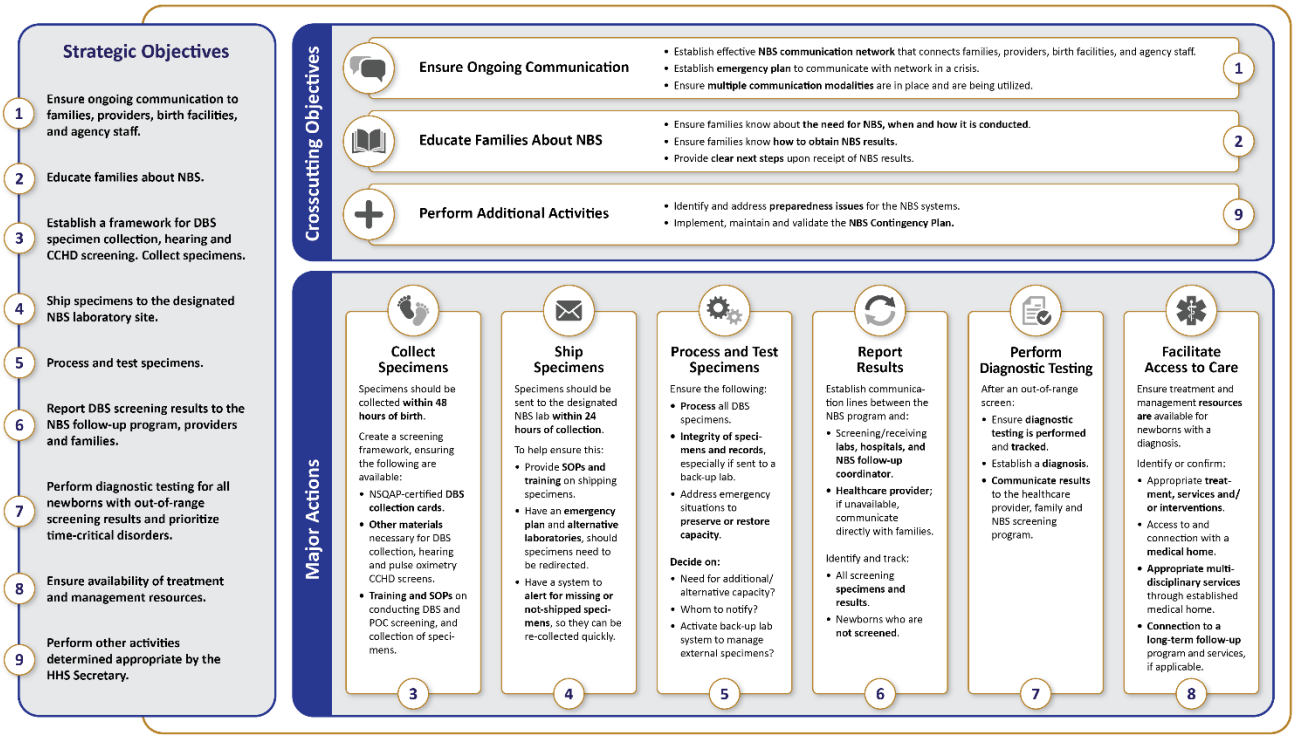
9. Manage the immediate response to the emergency.
10. Provide prospective information and education for employees and partners regarding roles and responsibilities during an emergency.
11. Maintain, exercise, or audit the COOP at least annually.

Strategic Objectives Flowchart

The flowchart in **Figure 1** provides an overview of strategic objectives and major actions that must be sustained to ensure that infants and their families receive these critically important services.

1. Ensure ongoing communication to families, providers, birth facilities, and agency staff.
2. Educate families about NBS.
3. Establish a framework for DBS specimen collection, hearing and CCHD screening.
4. Ship specimens to the designated NBS laboratory site.
5. Process and test specimens.
6. Report DBS screening results to the NBS follow-up program, providers and families.
7. Perform diagnostic testing for all newborns with out-of-range screening results and prioritize time-critical disorders.
8. Ensure availability of treatment and management resources.
9. Perform other activities determined appropriate by the HHS Secretary.

Figure 1. Strategic Objectives Flowchart (for a larger/more legible version of this flowchart, see p. 26). Note that this flowchart primarily contains activities related to dried bloodspot screening only.



I. Situation

A. Background

NBS has had a significant place in U.S. public health for decades. At the federal level, CDC and HRSA have provided guidance, coordination, and funded system-wide state NBS activities, including emergency preparedness.

In 2005, Hurricanes Katrina and Rita destroyed Louisiana's state public health laboratory and eliminated the state's ability to perform newborn DBS screening. Fortunately, the Iowa public health NBS laboratory, facilitated by the EMAC, was able to rapidly assume the screening of Louisiana's newborns. After the hurricanes, HRSA and APHL initiated a process to create regional NBS emergency preparedness plans and the CONPLAN. These plans were essential for preparedness and recovery from the effects of Superstorm Sandy in New Jersey and New York in 2012. These plans provided a roadmap for emergency preparedness for all jurisdictional NBS programs and address a variety of events that can disrupt routine NBS operations.

APHL has and continues to serve as a central point of contact during emergencies and assists programs in maintaining essential services. This work included APHL establishing a subcommittee of its Newborn Screening Committee to develop a framework to assist public health laboratories to prepare for, and respond to, disasters caused by nature, terrorism, and interruptions of testing materials and supplies in 2014. The subcommittee designed a checklist (**Appendix A**) that outlined the various elements that public health laboratories must address to prepare for disasters that disrupt newborn DBS screening program operations. A generic Model Memorandum of Understanding/Agreement (MOU/MOA) (**Appendix B**) was developed to include elements

for consideration by states that may need assistance from other states using a mutual assistance agreement. These documents were incorporated into CONPLAN Version II in August 2017.

To develop Version III of this Framework, APHL convened a task force of NBS experts and partners, including federal, state, and local governmental entities, and family representatives (**Appendix F**).

B. Authorities

- The Newborn Screening Saves Lives Reauthorization Act of 2014
- 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

C. Threat

A state and site vulnerabilities analysis provides a list of threats that might disrupt normal public health functions, including NBS program operations within laboratory facilities (e.g., laboratory testing) and within the community (e.g., patient follow-up, treatment). Such threats fall into the following general categories:

- Extreme weather conditions and natural disasters
- Civil disturbance
- Bioterrorism or other terrorism emergencies
- Chemical emergencies
- Radiation emergencies
- Cyberthreats
- Pandemics/Epidemics
- Extensive building damage or compromised building utilities
- Failed communication and information technology systems
- Major equipment failure
- Prolonged personnel staffing issues
- Supply chain disruptions

Each public health NBS program should develop a comprehensive list specific to its own facility. This list could be coordinated and/or informed by other organization analyses, such as a health department's Hazard and Vulnerability Analysis.

D. Critical Considerations

1. NBS needs must be elevated and maintained during any public health emergency.
2. Many states lack adequate resources to ensure self-sufficiency through internal back-up systems and redundancy through other states in their region.

3. Few states have the capacity to absorb a significant increase in hospital-based screens and screening volume for the laboratory and follow-up functions in the case of an emergency.
4. Because of variation in screening panels among states, contingency NBS programs that provide screening assistance to other states may not have the capacity to screen for all of the same conditions. Contingency NBS programs may also not have the capacity needed to follow up with newborns with a positive or out-of-range result.
5. Availability of treatment for NBS conditions may not be uniform across jurisdictions during a public health emergency.

E. Critical Assumptions

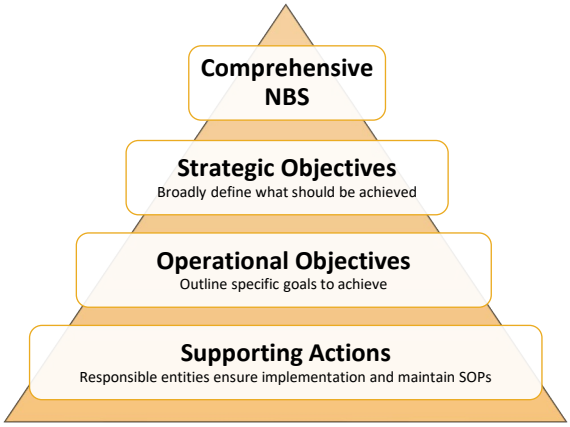
1. Babies continue to be born during all emergencies and remain the most vulnerable among the population.
2. National and/or regional back-up systems, including birthing facilities, must consider individuals in labor and are required to ensure continuity of NBS operations.
3. Preparations and drills for NBS contingencies must occur before the need for their implementation.
4. NBS contingency plans are developed by the NBS system, but successful implementation during an emergency involves partners outside the system.

F. Strategic and Operational Objectives and Supporting Actions

Strategic objectives broadly define what should be achieved to ensure comprehensive NBS. Operational objectives outline specific goals to achieve and require supporting actions that must be accomplished to fulfill the strategic objective. Each state should ensure that their NBS contingency plan is integrated into the overall state preparedness plan.

The NBS Contingency Planning Checklist (**Appendix A**) provides the strategic and operational objectives and major activities in a checklist format. The responsible entities for each action are also outlined in the Checklist. Each responsible entity must develop and maintain specific standard operating Procedures (SOPs) that detail how each activity is executed within their jurisdiction or scope of responsibility. SOPs should be reviewed and updated according to regulatory requirements to ensure they reflect current operations. The strategic objectives are supported by specific operational objectives, which are further supported by supporting actions (**Figure 2**). Each action has an entity that is responsible for ensuring proper implementation of the activity.

Figure 2: NBS Strategic Objectives, Operational Objectives and Actions



II. Oversight

A. Emergency Management Assistance Compact

The EMAC is a national interstate mutual aid agreement that enables states to share resources during times of disaster. EMAC provides a structure for emergency support between states where requested resources can be shared. EMAC was established by a federal law (Public Law 104-321) and ratified by Congress in 1996. All 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands are EMAC members and have each enacted essentially uniform EMAC legislation which authorizes participating states to provide assistance and share resources during a state of emergency declared by the jurisdiction's governor. Sharing of resources and provision of assistance under EMAC requires the declaration of a state of emergency by the jurisdiction's governor.

The National Emergency Management Association administers the EMAC program. The Framework considers EMAC an essential resource in supporting emergency preparedness and response for NBS. Each state's EMAC statutes contain provisions pertaining to liability, reimbursement, licenses and related requirements for public health programs such as NBS (laboratory and follow-up) during a declared emergency. EMAC establishes a legal foundation for sharing resources between states and thus addresses the problems of liability and responsibilities of cost and allows for credentials, licenses, and certifications to be honored across state lines. For example, under EMAC, a state requirement to screen for specific conditions may be set aside for a period of time during an emergency. Additionally, EMAC may be used during preparedness exercises with the same protections as during a true emergency. Therefore, EMAC laws should be reviewed when developing a contingency plan as they can inform what is currently written in state law and what points remain to be addressed.

It is important to note that not all events that would require activation of a NBS contingency plan result in the declaration of an emergency by a state's Governor. Advance coordination with a state Governor to clarify NBS as an essential public health service could facilitate rapid declaration of a limited state of emergency to invoke EMAC should anything disrupt the NBS system. That said, while limited states of emergency could be declared related to NBS, programs must plan for a multitude of events that disrupt essential functions without the

ability to use EMAC. Thus, the development of agreements including but not limited to MOAs/MOUs and contracts in advance of an event is critical for an effective response where EMAC is not utilized.

B. Legal Issues Involved in Interjurisdictional Agreements for NBS Contingency Planning

Numerous legal issues must be considered in developing a contingency plan for NBS emergency preparedness. MOA/MOU and contracts with those involved to provide backup services, interstate compacts, and other agreements can address issues the state's rules typically cover, including return and storage of materials, malpractice and liability of responders, and other factors. The considerations outlined in this section may be useful when entering an MOU or contract with another state. They are drawn from the APHL/CDC Policy Guide for Public Health Laboratory Test Service Sharing and CDC's guidance publication, An Overview of legal considerations in assessing multijurisdictional sharing of public health laboratory testing services; for more information on any of the considerations below, see the above linked documents.

1. Authority to Participate in Test Service Sharing

Although there is no express legal authority to enter into formal test service sharing agreements across jurisdictions, this is generally not precluded.

2. Liability and Payment

Two common concerns encountered in developing formal test service sharing agreements are the extent to which one state laboratory may be held liable for another state laboratory's actions or omissions to act (i.e., liability) and how funds are transferred from one state laboratory to another (i.e., payment). These concerns rank high as frequent barriers to test service sharing and should be discussed while developing the agreement.

Liability

Negotiation of liability considerations should identify and allocate responsibility for possible risks involved in test service sharing between jurisdictions. For example, states may include indemnification provisions to specify which parties agree to compensate others for loss or damages incurred as a result of pre-defined incidents, such as inaccurate reporting of results, misuse or misplacement of specimens, and/or breaches of privacy.

Payment

The ways in which state laboratories charge for test services performed in another state vary widely. Some jurisdictions prohibit these charges, some specify a fixed amount, some charge the fee from the state in need, and some permit full cost recovery, with certain laws exempting specific tests from being charged.

3. Certification and Licensure

Laboratories

The Clinical Laboratory Improvement Amendments of 1988 (CLIA) designate the provisions needed to permit testing of human specimens, including NBS specimens, for the prevention, diagnosis, or treatment of diseases.

While CLIA likely does not preclude shared service agreements, it may be helpful to include a provision that addresses all necessary laboratory certifications.

Personnel

Some states have laboratory personnel licensure requirements, and many of these states require out-of-state laboratories to comply with these requirements when sharing test services. In addition, many states require certification or licensure for personnel performing certain follow-up functions (e.g., genetic counselors, nurses).

4. Privacy

Public health laboratories, including NBS programs, are subject to federal and state laws that protect individuals' privacy and the confidentiality of information related to their health. Of particular note are federal laws – the Health Insurance Portability and Accountability Act (HIPAA) and Health Information Technology for Economic and Clinical Health Act (HITECH) – and state-specific genetic privacy laws.

HIPAA (1996) protects information that "identifies an individual or for which there is a reasonable basis to believe the information can be used to identify the individual" and was updated and strengthened in 2009 via HITECH. That act regulates the disclosure of patient-identifiable information by covered entities (e.g., health care providers, health plans, and health clearing houses) and their business associates (e.g., claims processors and data services) to public health entities. Public health laboratories are often considered covered entities (i.e., when located within a health department) or hybrid entities – and thus HIPAA compliance is mandatory. It will be important to clarify which state laboratories are covered entities, hybrid entities, or business associates when entering into shared service agreements.

State privacy laws must also be considered. These laws often serve to supplement, and in many cases surpass HIPAA protections, so provisions may need to be set in place to ensure these laws do not impact implementation during an emergency.

5. Disease Reporting Laws

Although state-specific reporting requirements (i.e., who is required to report, which diseases are reportable, to whom reports must be made, reporting time frames, report content, reporting methods, etc.) may influence shared service agreements and should be reviewed for potential implications, it is uncommon for these requirements to raise specific challenges.

6. In-State vs. Out-of-State Testing

While most states conduct their own testing and follow-up of newborns within their borders, several states may participate in a contractual agreement in which specimens are sent to a centralized testing facility and results are sent back to the original state for follow-up.

For states that have a standing, nonemergency agreement for inter-jurisdictional testing, the same agreements may apply during an emergency. For states that do not, it may be useful to define a plan of action for inter-jurisdictional test sharing during a declared emergency, such as agreeing to only test for disorders typically tested for in the original state or the return of specimens and data to the original state at the end of the emergency for additional testing or storage of residual specimens. Additional considerations for conducting out-of-state emergency testing may include (but are not limited to): timeliness of testing and reporting; one-

versus two-screen states; fees for screening; parental consent (more on this below) and mechanism of reporting (electronic, fax, telephone).

7. Parental Consent

While NBS is opt-out across the country, states vary in opt-out or refusal procedures (e.g., for what reasons one can opt out, forms required, etc.). States should review their own refusal procedures and the procedures of jurisdictions they plan to enter into an agreement with, which will inform the language and provisions used in any agreement vehicle (e.g., State A and State B agree that State A will abide by State B's refusal requirements to test for specific diseases in an emergency).

III. Execution

A. Partners for Engagement

The successful development, assessment, activation, and evaluation of contingency plans requires multiple partners including, but not limited to, the following groups.

Federal Agencies

- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services
- Department of Defense
- Federal Emergency Management Agency
- Health Resources and Services Administration (HRSA)
- Indian Health Service

City, County, Tribal and State Agencies

- State and local public health departments
- State and local public health laboratories
- State and local public health preparedness
- State and local emergency management
- State attorney general
- State homeland security
- State NBS programs
- State Title V Maternal Child Health / Children and Youth with Special Health Care Needs
- Tribal governments and health agencies

Non-governmental Organizations and National Partners

- American Academy of Family Physicians
- American Academy of Pediatrics
- American College of Cardiology
- American College of Medical Genetics and Genomics
- American College of Obstetricians & Gynecologists
- American Heart Association
- Association of American Indian Physicians
- Association of Maternal & Child Health Programs (AMCHP)
- Association of Public Health Laboratories (APHL)
- Association of State and Territorial Health Officials
- Association of Women's Health, Obstetric & Neonatal Nurses
- Child Neurology Society
- Genetic Alliance
- Hospital associations
- Joint Committee on Infant Hearing
- March of Dimes
- Manufacturers and vendors of NBS tests and supplies
- National Association of County and City Health Officials
- National Center for Hearing Assessment and Management
- National Emergency Management Association / Emergency Management Assistance Compact (EMAC)
- National Society of Genetic Counselors
- Patient Advocacy groups
- Regional disaster organizations
- Society for Inherited Metabolic Disorders

Healthcare Service Partners

- Academic laboratories
- Case managers
- Clinics
- Commercial laboratories
- Hospitals
- Payors
- Primary care and other physicians, nurses, and allied health practitioners
- Specimen delivery systems
- Suppliers of dietary management products, metabolic nutritionists and partners involved in dietary management

B. Pre-alert Responsibilities

It is outside the scope of this plan to address state-specific details for NBS contingency planning. However, a state can ensure a smoother assistance process by being proactive and with a contingency plan in place.

State Health Official

- Develop a state COOP Plan.
- Test the plan internally and apply it to different scenarios.
- Meet with Public Health Preparedness Director and EMAC coordinator to discuss NBS contingency planning.

  Establish a contingency plan that includes the point-of-care, laboratory, and follow-up requirements for the NBS program.

  Coordination at all levels is imperative. Consider pre-identifying potential reciprocal laboratories and/or entering into MOUs/MOAs with several partner states in different geographic regions. Identify hospitals that are appropriate to accept a transferred newborn needing immediate evaluation for a failed CCHD screen and a hospital or diagnostic center to diagnose hearing loss, if managed by the NBS Program. Consider developing a shared response which could ease 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. Redundancy should be planned in-depth, such as multiple methods to respond to a system or component failure or a secondary response identified should the primary backup fail. Evaluate each aspect of the NBS program and determine what would happen if any or every aspect failed. If an aspect is critical to the NBS system functioning, develop backups for team members, equipment, facilities, and supplies.
  - Communication is critical. Interstate and intrastate communication is essential when the usual reporting mechanisms for NBS results or standard communication channels might be unavailable. It is important to include online reporting methods in the SOP.
  - Schedule regular (e.g., yearly) exercises and reviews of the contingency plan to test the response network.
  - Conduct drills. Consider performing joint emergency drills with reciprocal agreement states. Practice drills provide opportunities to examine quality assurance parameters.
  - Refer to **Section C**, Considerations for COOP Development (below), for recommended considerations regarding COOP planning.

  Amend or establish MOUs/MOAs to include NBS contingency planning.
- Establish contracts with partners and vendors to include NBS contingency planning.
- Establish and maintain ongoing engagement with tribes and tribal epidemiology centers.

Birthing Locations (Hospital and Out-of-Hospital)

- Establish a COOP covering required bloodspot, EHDI, and CCHD NBS.
- Assure specimen collection, testing, transport, tracking and results follow-up are included in the COOP.
- See **Operational Objectives 2, 3, 6 and 7** for additional details and considerations.

NBS Program (Laboratory and Follow-up)

- Identify alternate specimen transportation plans.
- Establish backup testing methods or plans.
- Obtain documentation that manufacturer or supplier has the following:
    - Adequate forward stocking established.
    - Adequate alternate consumables identified, should there be supply chain issues during an extended emergency.
    - Alternate transportation plans established.
- Work with manufacturers or suppliers to address situations where materials are not delivered as scheduled, such as:
    - Cost of alternative testing instruments, materials, or outsourced testing, and
    - Cost of staff time to implement alternate testing.
- Collaborate with state and federal agencies to harmonize laboratory methods and use of common data elements.
- Establish interstate and regional agreements (MOUs/MOAs) for ensuring backup of laboratory capacity in addition to EMAC (for situations where EMAC may not be activated).
- Establish back-up plans to ensure continuation of diagnosis and follow-up services for newborns with a positive or out-of-range result.
- Establish a public health laboratory COOP and ensure that NBS is included in it (See next section, **C**, for recommended considerations when developing a COOP).

Healthcare Providers

- Establish alternative methods to communicate with families.
- Identify mechanisms to share results with families and prioritize screen positive or out-of-range results for time-critical disorders.
- Collaborate with NBS Follow-up to identify diagnostic testing options and treatment centers.
- Collaborate with NBS Follow-up to identify populations that will be disproportionately affected during an emergency, those who live in medical deserts and what type(s) of outreach may be most effective or successful.

Manufacturers and Commercial Partners

Reagent and Equipment

- Adequate forward stocking established.
- Adequate alternate consumables identified, should there be supply chain issues during an extended emergency.
- Alternate transportation plans established including disaster identification to allow travel in an emergency.
- Plan to provide equipment, training, and/or supplies as needed to alternate site(s) within a specific time frame.

Information Technology

- Establish alternate access options.
- Identify different data flows for network failures.
- Plan to provide equipment for hardware failures.

Courier/Specimen Transport

- Alternate transportation plans/routes established.

C. Considerations for COOP Development for the NBS Program

A COOP applies to all operations, infrastructure, and resources necessary to continue the laboratory and follow-up 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. A COOP for a public health laboratory should have two basic features:

1. A NBS COOP provides a comprehensive, pre-identified list of all core testing, support activities, supplies, and communications plans to report positive or out-of-range screening results to healthcare providers or families if the laboratory experiences a partial or complete operational disruption; and
2. A COOP provides a prearranged plan of action to ensure that all core activities are continued without delay.

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. Preserve adequate facilities including:
    a. Electrical power
    b. Water (deionized)
    c. Refrigeration
    d. Heating and cooling
2. Perform essential processes such as:
    a. Specimen accessioning
    b. Demographic entry
    c. Testing
    d. Results reporting
3. Maintain a 3-month supply of testing materials. Identify alternate vendors of these materials, should there be supply chain issues.
4. Ensure secure communications through:
    a. Availability of data systems to record integrity and timely transmission of test results to providers and state programs
    b. Telephones for continuous access to communication.
    c. Maintenance of data security and patient privacy.

On-site Operation: Long-Term

1. Prioritize tests to be reported. Refer to the citations in Appendix D for the ACHDNC timeliness recommendations and Society for Inherited Metabolic Disorders (SIMD) statement on defining time-critical conditions.
2. Identify states and tribes with same screening panels and methodology and consider backup plans in the event of an emergency.
    a. Prepare for differences in testing algorithms and results interpretation introduced by different methods should states with similar panels and methodology be unavailable.
    b. Continuity of essential screening is more critical than identification of a contingency program with an identical panel. Time-critical conditions, as described in item (1) should be prioritized.
3. Identify states using common data elements with similar laboratory information management systems and reporting mechanisms (e.g., messaging, web-based, fax, and voice response system).

Off-site Operation

1. Identify contacts at offsite screening facility if specimens are being tested at a different laboratory.
2. Establish MOU with other NBS programs as needed to manage specimen volume. *See Appendix B for example.
3. Establish a plan for compensation.*
4. Establish a plan for specimen transport.
5. Establish a plan for communication of positive or out-of-range results to submitters, providers or specialists.
6. Establish a plan for communication of all test results to submitters.
7. Prepare for temporary relocation of staff.
    a. Identify in-house staff, and plan for updated emergency contact information.
    b. Identify financial mechanisms for travel and housing.
    c. Identify follow-up staff who can work remotely and assess technology needs to comply with remote privacy/data security requirements.
    d. Establish staffing rotation to provide relief from duty.
8. Establish a plan for access, retrieval, and entry of all data into local information system after local operation is reestablished.
9. Establish a communication plan for the development and delivery of public service announcements to inform hospitals, midwives, providers, and the public of process changes.
10. Establish a plan for return to normal operations.

Activation and Deployment

The COOP should identify those triggers that would result in the activation of certain contingency plan activities. Resources will be deployed as needed based on the event, program activities impacted, and partners required for the response. Depending on the nature of the event and program activities impacted, the turn-around time for results may be affected and these impacts must be communicated.

D. Demobilization

Procedures for standing down the plan should be developed and issued by appropriate state authority (as required). An after-action report is a critical step to assess the effectiveness of the response and identify opportunities for improvement.

* EMAC, if activated, will provide MOUs and reimbursement of eligible mission costs.

IV. Coordination And Communications

A. Coordination

Pre-event Planning and Exercises

Contingency plans are only as good as the preparation to employ them. Periodic conferences that discuss details of NBS contingency plans and MOU/MOAs are highly beneficial tools to maintain attention on these plans and allow for periodic updates as needs or situations warrant. All partners in the NBS system (section III.A.) must assume overlapping responsibility for the continuation of all aspects of the program.

Plans, MOUs, and MOAs should be reviewed and revised at least every 5 years. References, links, and contact information in preparedness documents should be verified at least annually.

Event Activation

During a public health emergency, organizations may employ an incident command system (ICS) or modified ICS to coordinate the various aspects of the response. Periodic training on the ICS and exercising of contingency plans will facilitate a successful and efficient event activation and resource deployment.

Post-event Review

At the conclusion of a public health emergency, it is critical to conduct an after-action review of the event response. This assessment should include all partners, including those not involved in the specific emergency, to review the event and identify opportunities for improvement. At the conclusion of the review, an after-action report should be distributed to all partners and relevant documents updated to reflect lessons learned.

B. Communications

Effective NBS communications support involves addressing issues that arise during the course of normal operations and planning, as well as COOP. Recommendations for consideration and inclusion in planning are outlined in Strategic Objective 1.

Implementation requires immediate activation of the COOP notification team to contact the following key individuals and groups to provide them with essential information and guidance:

- All required response teams.
- State and Tribal Nations Health Officer.
- State and Tribal Nations epidemiologist.
- Title V Children and Youth with Special Health Care Needs (CYSHCN) Director. State and Tribal Nations Emergency Management.
- All affected agency leaders.
- All laboratory staff.
- All NBS program staff.

- All affected submitters of samples and specimens.
- All alternative laboratories and NBS programs that may be required to assume core functions.

Appendices

Appendix A. Strategic Objectives Flowchart and Newborn Screening Contingency Planning Checklist Framework

Appendix B. Model Memorandum of Understanding/Agreement (MOU/MOA)

Appendix C. Additional Resources

Appendix D. References

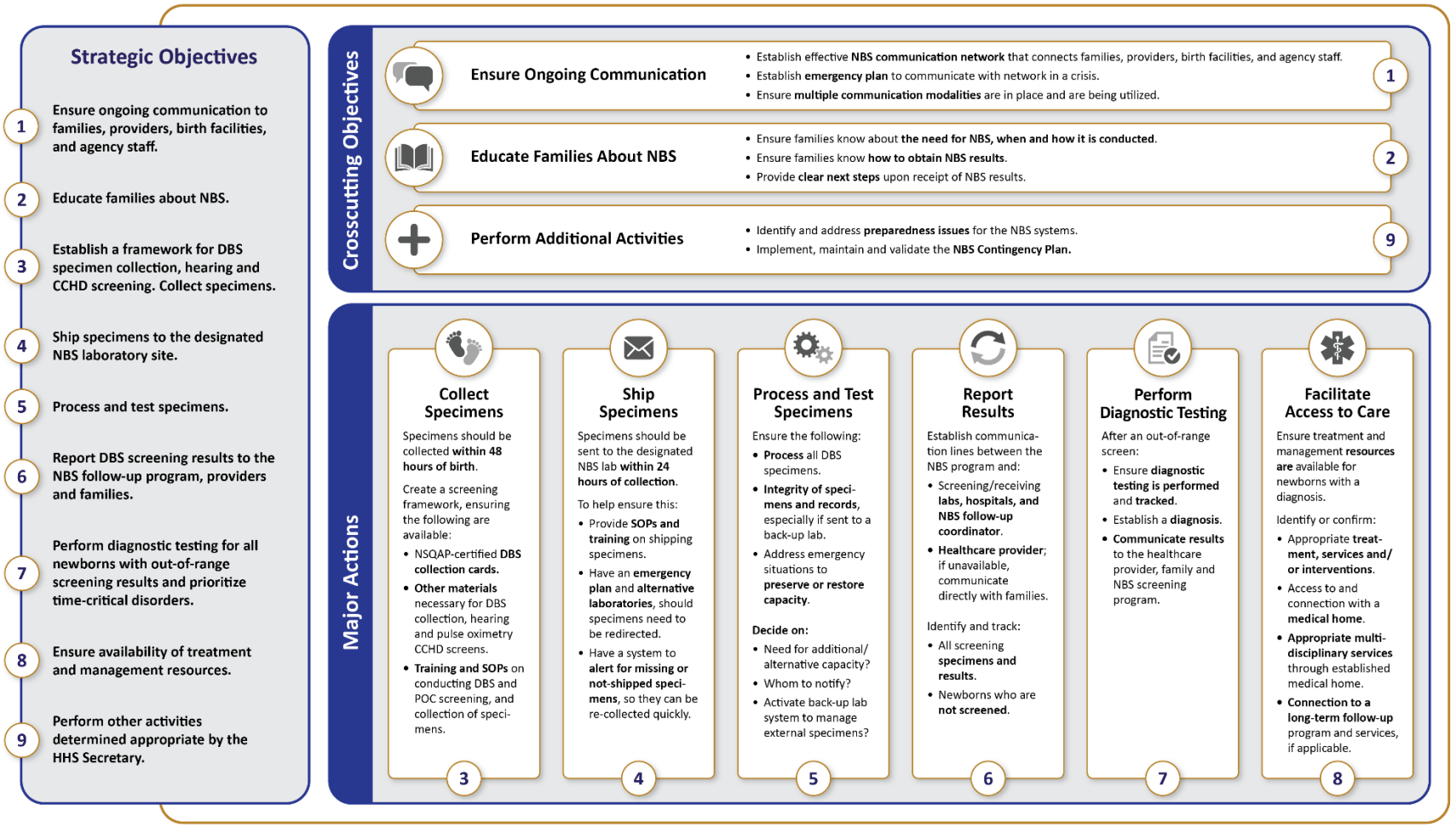
Appendix E. Acronyms

Appendix F. CONPLAN Update Advisory Committee Members (2023-24)

Appendix A. Strategic Objectives Flowchart and Newborn Screening Contingency Planning Checklist Framework

NBS CONPLAN STRATEGIC OBJECTIVES FLOWCHART

The flowchart below provides an overview of strategic objectives and major actions that need to be sustained to ensure babies and their families receive these critically important services.



Newborn Screening Contingency Planning Checklist Framework

This checklist includes the strategic objectives, operational objectives, and major supporting actions that should be considered when planning and preparing for NBS contingency operations. Not all emergency situations are the same and not all identified items may be needed. Additionally, there may be other items and issues that will need to be addressed that are not included in this plan.

Strategic Objective 1 Ensure ongoing communication to families, providers, birth facilities, and agency staff.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
1.1 Establish an effective NBS communication network that connects families, providers, birth facilities, and agency staff.	External Communications: Establish relationships with and identify contact information for/established relationships with the following: ☐ Birth facilities – nursery and laboratory ☐ Known midwives ☐ Local family practice and pediatrician groups ☐ Appropriate specialists ☐ Families already identified with a newborn screening condition Employ multiple communication modalities: ☐ Phone: ☐ Emergency call-back systems ☐ Integrate with Health Alert Network ☐ Social Media (Facebook, Twitter) ☐ Text ☐ Email ☐ Family resource centers (e.g., state Family to Family Health Information Center, Family Voices, Genetic Alliance) ☐ Radio & Television ☐ Program/Agency ☐ Website updates ☐ Streaming audio sessions Provide education and training on state newborn screening practices to the following: ☐ Families ☐ Providers ☐ Birthing facilities/midwifery practices ☐ Ensure education and preparedness messages are linguistically and culturally appropriate; communications are accessible to all populations; and that communication channels are in place for reaching all affected populations. ☐ Incorporate emergency processes into standard communications to NBS system partners	☐ Ensure all NBS system partners are aware of the existence of a contingency plan. ☐ Consider social media as an internal communication mechanism. ☐ For websites, consider a designated area or state communication portal for emergency information.	State: • State Health Official • NBS Program Director • State Early Hearing Detection and Intervention (EHDI) Coordinator • Title V MCH/ CYSHCN program • State Hospital Preparedness Director • State Preparedness Director • State Emergency Management Director or designee Local: • Jurisdictional public health authority • NBS program • Laboratory(ies) • Local Emergency Management

Strategic Objective 1 Continued **Ensure ongoing communication to families, providers, birth facilities, and agency staff.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
	Internal Communications: ☐ Define a call-back system for in-house staff and NBS system partners. ☐ Review and update the system at least semiannually. ☐ Store critical data needed for activation of the COOP at an off-site location (or location accessible remotely) for ready access. ☐ Store necessary contact information for staff, stake- holders, couriers, alternate laboratories, vendors, emergency management personnel, and key contact information for APHL, CDC, and HRSA on a secure site available remotely and/or on back-up servers that are housed in other areas. ☐ Store any relevant standard operating procedures needed to carry out COOP activities on a secure site available remotely.		
1.2 Establish emergency plan to communicate with network in a crisis.	☐ Determine which types of emergency will require emergency communications and to whom. ☐ Create centralized communication hotline for newborn screening. ☐ Educate NBS system partners on how they will receive information about newborn screening in an emergency. ☐ Incorporate the National Standards for Culturally and Linguistically Appropriate Services (CLAS) into preparedness activities: ☐ Perform needs assessment and gap analysis. Develop key messages in appropriate languages in advance of emergency situations. ☐ Establish a plan for communication that is accessible to all populations, including deaf and hard of hearing, blind and low vision consumers. If your jurisdiction contains medical deserts and/or particularly vulnerable, remote, or historically excluded populations, have meaningful plans to perform outreach to these populations using alternate communication mechanisms as required.	Consider developing a specific communication plan and channels with alternative/ back-up screening entities. Other situations or points to consider: ☐ Personnel shortages (e.g., strikes) ☐ Consider cross-training ☐ Loss of supplies (NBS kits) ☐ Hospital evacuation ☐ Electronic medical records system (EMR) goes down	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • State Hospital Preparedness Director • State Preparedness Director • State Emergency Management Director or designee **Local:** • Jurisdictional public health authority

Strategic Objective 1 Continued **Ensure ongoing communication to families, providers, birth facilities, and agency staff.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
			• NBS program • Hospital Incident Command Staff • Birthing Facilities • Laboratory(ies) • Local Emergency Management
1.3 **Ensure multiple communication modalities are in place and are being utilized.**	Establish a variety of communication modalities, including: ☐ Agency email listserv ☐ Organizational listservs (e.g., APHL, AAP, etc.) ☐ Phone hotline (e.g., Health Alert Network or State HAN Coordinator) ☐ Social media (Facebook, Twitter) ☐ Text ☐ Family support groups and community networks ☐ Program/Agency Website ☐ Fax	Maintaining email and/or contact lists can be challenging: ☐ Use a hotline ☐ Establish a master contact list and update it periodically Social media venues to consider could include: ☐ Agency/ Program ☐ External partner organizations (Expecting Health, APHL, family support groups, etc.)	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • State Hospital Preparedness Director • State Prepared-ness Director • State Emergency Management Director or designee **Local:** • Jurisdictional public health authority

Strategic Objective 2 Educate families about NBS.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
2.1 **Ensure families know about the need for NBS, when and how it is conducted.**	☐ Identify pregnant women and families with newborn babies. ☐ Deliver information about NBS at the time the specimen is obtained or point-of-care screening is performed. ☐ Ensure families understand the information. ☐ Raise awareness of the public health functions of the state NBS program.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • State Hospital Preparedness Director **Local:** • Jurisdictional public health authority • Birthing or screening facility. • NBS program • Families
2.2 **Ensure families know how to obtain NBS results.**	☐ Provide families with information and education on how to obtain screening results. ☐ Include state emergency agencies' contact information in documents and information distributed to families. ☐ Request alternate/emergency contact information for family on the NBS specimen kit. ☐ Include additional contact options (healthcare provider, state health department, etc.) at the bottom of the state testing pamphlet and a statement that parents should ask their pediatrician about NBS results at baby's first visit. ☐ Ensure that families know about point-of-care screening results prior to discharge. The baby with a failed CCHD screen will be evaluated prior to discharge from the hospital or birthing facility. ☐ If a newborn fails a hearing screen, families should receive results and follow-up appointment information.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • State Title V MCH/CYSHCN program • State Hospital Preparedness Director **Local:** • Birthing or screening facility • Healthcare providers • NBS program • Families

Strategic Objective 2 continued **Educate families about NBS.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
2.3 **Provide clear next steps upon receipt of NBS results.**	Assist families with appropriate course of action: ☐ Provide families information about access to care. ☐ Provide families with information on the potential meaning of a positive or out-of-range result and need for confirmatory testing for diagnostic purposes. ☐ If testing confirms a diagnosis, provide information on short-term follow-up and linkage to specialty care.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • State Title V MCH/CYSHCN program • State Hospital Preparedness Director **Local:** • Birthing or screening facility • Healthcare providers • NBS program • Families

Strategic Objective 3 **Establish a framework for DBS specimen collection, hearing and CCHD screening. Collect specimens.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
3.1 **Ensure that NSQAP-certified blood spot collection cards are available.**	☐ Contact the Association of Public Health Laboratories (APHL) to request emergency blood spot collection cards from CDC's NSQAP. ☐ Ensure cards are not expired. ☐ Facilitate redistribution of locally available cards until supplies are exhausted. ☐ Notify and 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.		**State:** • State Health Official • NBS Program Director • State Hospital Preparedness Director **Local:** • Jurisdictional public health authority • Birthing or screening facility • NBS program • Families

Strategic Objective 3 continued **Establish a framework for DBS specimen collection, hearing and CCHD screening. Collect specimens.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
3.2 **Ensure that other materials necessary for DBS collection, hearing and pulse oximetry CCHD screens are available.**	☐ Ensure availability of materials required for blood spot collection, including lancets, alcohol pads, and packaging at hospitals and other potential collection sites. ☐ Ensure availability of materials for CCHD screening, including pulse oximeters and probes designed for use in newborns, equipment and personnel for follow-up echocardiogram (on-site or by telemedicine), or identification of an alternate site with proper materials for further evaluation. ☐ Ensure availability of materials for hearing screening, such as OAE and ABR screening equipment and necessary supplies (e.g., probes).		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • State Hospital Preparedness Director **Local:** Hospitals and other potential collection and screening sites
3.3 **Ensure that training materials and SOPs on conducting DBS and POC screening, and collection of specimens are available.**	☐ Train medical professionals who may be involved in dried blood spot collection. ☐ Train professionals who may be involved in conducting a CCHD screen on the jurisdiction's defined protocol. Train professionals who may be involved in conducting a hearing screen using physiologic measures, such as OAE and/or automated ABR testing. ☐ Collect appropriate specimens and conduct appropriate point-of-care screens. ☐ Record accurate demographics and results of point-of- care screenings (to allow complete screening, including follow-up testing). ☐ Maintain a log of all dried blood spot specimens collected or refused at the collection site. ☐ Decide which laboratory to use. Identify alternate courier (if necessary) who will work in any emergency/disaster conditions (e.g., National Guard, state police, FedEx or UPS, local couriers, etc.). Inform hospitals and follow-up providers about changes in laboratory and/or couriers. ☐ Forward completed and dried blood spot specimen to shipping location. ☐ Report CCHD and hearing screening results to appropriate state program. ☐ Evaluate any newborn with a failed CCHD screen for the cause of low blood oxygen levels including CCHD prior to hospital discharge. Establish plans for transfer to another facility when indicated.		**State:** • State Health Official • State Preparedness Director • NBS Program Director • State EHDI Coordinator • State Hospital Preparedness Coordinator **Local:** • Hospitals and other potential collection and screening sites • NBS program • State hospital preparedness coordinator • Hospital or alternate evaluation facility

Strategic Objective 4 Ship specimens to the designated NBS laboratory site within 24 hours of collection.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
4.1 **Provide SOPs and training on shipping specimens.**	☐ Assess the situation and the operational status of laboratories and transport system. ☐ Identify alternate courier (if necessary) who will work in any emergency/disaster conditions (e.g., National Guard, state police, FedEx or UPS, local couriers, etc.). Inform hospitals and follow-up providers about changes in laboratory and/or couriers. ☐ Train medical professionals who may be involved in dried blood spot specimen transport. ☐ Ship to primary laboratory, if available. Ship to secondary or tertiary laboratories when necessary. ☐ Operationalize tracking system to document chain of custody of specimens. ☐ Maintain a log of all dried blood spot specimens packaged and transported. ☐ Notify courier of any special pick-up or delivery issues (e.g., timing, or location).	Weather-related impacts to transportation routes or courier strikes may present the need to consider alternate couriers: ☐ Consider local and state public entities, such as the National Guard, local police and fire personnel, the State High-way Patrol, and Sheriff's Department as potential alternative couriers.	**State:** • State Health Official • NBS Program Director • State Preparedness Director • State Hospital Preparedness Director **Local:** • Jurisdictional health official • NBS Program Coordinator(s) • Public Health and Hospital Preparedness Coordinators • Hospital and other potential collection facilities • Laboratory(ies) • Local Emergency Management
4.2 **Have an emergency plan in place and alternative laboratories selected, should specimens need to be redirected.**	☐ Notify courier of any special pick-up or delivery issues, if not already done. ☐ Contact transport system provider and execute change of address.	☐ Consider centralized courier pick-up site.	**State:** • State Health Official • NBS Program Director • Courier services **Local:** • NBS programs • Hospitals and other potential collection sites • Laboratory(ies) • Courier Services • Local Emergency Management

Strategic Objective 4 continued **Ship specimens to the designated NBS laboratory site within 24 hours of collection.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
4.3 **Have a system to alert for missing or not-shipped specimens, so they can be re-collected quickly.**	☐ Identify missing specimen(s). ☐ Contact the newborn's provider and birth hospital. ☐ Locate the newborn and newborn's family. Collect a second specimen. ☐ Use Public Service Announcements (PSAs) to aid in advising parents of newborns affected by an emergency incident when necessary.		**State:** • State Health Official • NBS Program Director • State Hospital Preparedness Director **Local:** • Hospitals and other potential collection facilities • Laboratory (ies) • NBS program staff • Health care providers • Joint Information Center (JIC)

Strategic Objective 5 Process and test specimens.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
5.1 **Assess laboratory capability and capacity.**	☐ Assess facilities, supplies, reagents, utilities, staff, informatics, supply chain, transport systems, safety issues or working environment, and communication systems. ☐ Assess potential duration of interruption and disruption of lab capacity or service. ☐ Document assessment.	*Situations you may want to consider:* **Shortage of reagents or other laboratory supplies or materials** **Power outage:** ☐ Have back-up power (batteries, generator) on-hand ☐ Be on priority list with power company **Breakage of laboratory equipment, machinery or technology:** ☐ Examine maintenance contracts **Personnel short-age (illness, in-ability to get into office, reassigned or detailed elsewhere):** ☐ ID essential personnel ☐ Provide letter/ card to identify essential personnel ☐ Identify back-up staff ☐ Identify emergency transportation assets	**State:** • State Health Official • NBS Program Director • State Preparedness Director • State Hospital Preparedness Director **Local:** • Jurisdictional health official • NBS Program Coordinator(s) • Public Health and Hospital Preparedness Coordinators • Hospital and other potential collection facilities • Laboratory(ies) • Local Emergency Management

Strategic Objective 5 continued Process and test specimens.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
5.2 **Ensure integrity of specimens and records, especially if sent to a back-up laboratory.**	☐ Evaluate potential risk to specimens and records. ☐ Take appropriate actions to ensure integrity of specimens and records. ☐ Make a record of damaged or compromised specimens and records.		**State:** • State Health Official • NBS Program Director • Back-up laboratory(ies) **Local:** • Hospitals and other potential collection facilities • Laboratory (ies) • NBS program staff • Health care providers
5.3 **Address emergency situations to preserve or restore capacity.**	☐ 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 record of any repairs made.		**State:** • State Health Official • NBS Program Director **Local:** • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management
5.4 **Decide whether additional or alternative capacity is needed.**	☐ 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.		**State:** • State Health Official • NBS Program Director **Local:** • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management

Strategic Objective 5 continued **Process and test specimens.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
5.5 **If additional capacity is needed, seek assistance or activate back-up plan.**	☐ Contact APHL and NewSTEPs. ☐ Contact State Emergency Manager with recommendations on the need to activate EMAC, if applicable. ☐ Identify and contact back-up laboratory. ☐ Ensure that the back-up laboratory is CLIA-approved and participates in the CDC NSQAP. ☐ Establish disorder panel needs. ☐ Identify and address or resolve major algorithm, information technology (IT), and methodological or protocol differences.		**State:** • State Health Official • NBS Program Director **Local:** • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management
5.6 **Notify appropriate internal and external NBS system partners (including personnel) of the change in process during an emergency.**	☐ Notify personnel according to internal procedures. ☐ Notify external NBS system partners, State Health Officer, State Title V CYSHCN Director, providers and sub-specialists, and the public, as needed.		**State:** • State Health Official • NBS Program Director **Local:** • Hospitals and other potential collection facilities • Laboratory (ies) • Courier services • Local Emergency Management
5.7 **Maintain a record of all dried blood spot specimens sent to and received by the back-up laboratory.**	☐ 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.		**State:** • State Health Official • NBS Program Director **Local:** • Hospitals and other potential collection facilities • Laboratory (ies) • Courier services

Strategic Objective 5 continued **Process and test specimens.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
5.8 **Activate a system at the back-up laboratory for managing external specimens from routine collections.**	☐ Back-up laboratories sort external specimens.		**State:** • State Health Official • NBS Program Director **Local:** • Back-up laboratory(ies)
5.9 **Specimens are analyzed and results are reported.**	☐ 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. ☐ Return specimen to originating state.		**State:** • State Health Official • NBS Program Director **Local:** • Back-up laboratory(ies) • NBS program • Health care providers

Strategic Objective 6 Report DBS screening results to the NBS follow-up program, providers and families.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
6.1 Establish communication lines between the sending and receiving laboratories, hospitals, and NBS follow-up coordinator(s).	☐ Assess options for communication among laboratories, hospitals performing CCHD and hearing screenings, and NBS follow-up coordinator. ☐ Formulate communication strategy. ☐ Implement strategies for communication.	*To address variability in reporting, consider:* ☐ Discussing data definitions, reporting verbiage and interpretations within communications strategy. *If database for laboratory is unavailable, consider:* ☐ Developing alternate method to report results to short-term follow-up and health care providers.	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Emergency management **Local:** • NBS program • Healthcare provider • NBS follow- up coordinator • Families • Emergency management
6.2 Establish communication lines between the NBS follow-up program and healthcare provider; if unavailable, communicate directly with families.	☐ Determine if newborn screening card submitter or physician of record is available. ☐ Identify alternative provider to report results, if needed. Report results to submitter or physician of record or alternative provider. ☐ Healthcare provider confirms to NBS coordinator that newborn is in care. **If healthcare provider is not available:** ☐ Locate family. ☐ Inform family of newborn screening results and need for additional care. ☐ Link family to healthcare provider, ultimately a primary care provider/medical home.	*If contact numbers for healthcare providers and specialists are electronic only:* ☐ Develop and maintain alternate method to store contact information for healthcare providers and sub-specialists	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Emergency management **Local:** • NBS program • Healthcare provider • NBS follow- up coordinator • Families • Emergency management

Strategic Objective 6 continued **Report DBS screening results to the NBS follow-up program, providers and families.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
6.3 **Track all screening specimens and results.**	☐ Develop a registry of specimens collected, and hearing and CCHD screens performed or refused. ☐ Record all results – positive or out-of-range, borderline, and negative or within normal limits – in registry. ☐ Resolve all open newborn screening follow-up cases.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Hospitals and other potential collection and screening sites • Health care providers • NBS follow- up coordinator
6.4 **Identify newborns who are not screened.**	☐ Match screening records with birth records to identify newborns not screened. ☐ Contact families of newborns who did not receive NBS.	*Depending on the emergency event and systems impacted, obtaining birth records may be difficult. Consider:* ☐ Documenting alternative approaches in advance. *To contact families, consider:* ☐ Public service announcements (PSAs) for those who did not know if their baby was screened to call a hotline where the data can be queried to confirm if the baby was	**State:** • State Health Official • NBS Program Director **Local:** • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management

		screened and valid results were obtained. ☐ Consider PSAs in your state and surrounding states to which residents may have relocated.	

Strategic Objective 7 **Perform diagnostic testing for all newborns with out-of-range screening results and prioritize time-critical disorders.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
7.1 **After an out-of-range screen, ensure diagnostic testing is performed and tracked.**	☐ Healthcare provider consults with appropriate sub-specialist. ☐ Healthcare provider identifies indicated diagnostic test(s) and laboratories. ☐ CCHD should be ruled out by a medical evaluation, which may include the use of diagnostic echocardiography that may involve transport to another facility if the birthing hospital is not equipped with echocardiography or telemedicine. ☐ Collect and send samples to diagnostic laboratories. ☐ Report newborns who do not pass the hearing screening to the state EHDI program along with information about if and to whom a referral was made. ☐ Report diagnostic test results to appropriate healthcare professionals, sub-specialists, designated state programs, or sample submitters as applicable.	☐ If the case management system (CMS) and/or the laboratory information management system (LIMS) are unavailable or cannot be accessed remotely, consider an alternate plan to document follow-up actions until database is re-established. ☐ If getting to follow-up care is difficult for families, consider telehealth options, if available.	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Hospitals and other potential collection and screening sites • Health care providers • NBS follow- up coordinator
7.2 **Establish a diagnosis and communicate results to the healthcare provider, family, and NBS program.**	☐ Healthcare 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. ☐ Notify NBS program of results and diagnosis.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Health care provider(s) • NBS follow- up coordinator • Families

Strategic Objective 8 Ensure availability of treatment and management resources.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
8.1 Identify appropriate treatment, services, and/or interventions.	☐ Identify a primary care provider and specialist(s). ☐ Appropriate healthcare provider and sub-specialist confer and discuss treatment recommendations and services and discuss with family. ☐ Provide acute or urgent care, if needed. ☐ Ensure newborns identified with hearing loss are referred to the state early intervention (Part C) program. ☐ Confirm each child's access to and connection with a medical home, as applicable.	☐ In an emergency, it may be challenging to identify or confirm a medical home. Once the immediate situation resolves, the need for a reconnection to a medical home can be emphasized. ☐ The medical home is the source for a complete and accessible record of a baby's medical history and can provide this information in an emergency. ☐ Consider telehealth options as needed, if available.	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Healthcare provider(s) • NBS follow- up coordinator • Laboratory(ies) • Families

Strategic Objective 8 continued **Ensure availability of treatment and management resources.**			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
8.2 **Confirm access to and connection with a medical home for delivery of appropriate multidisciplinary services.**	As applicable, ☐ Establish a mechanism to track affected displaced populations. ☐ Initiate chronic condition management. ☐ Initiate care coordination between primary care provider and specialist(s). ☐ Refer to State Title V CYSHCN Program, CYSHCN services, early intervention and/or community-based organization(s), and local resources to ensure access to needed services and family support. ☐ Develop a treatment plan. ☐ Facilitate access to counseling and social services. ☐ Facilitate access to medical foods, pharmaceuticals, and devices. ☐ Establish reimbursement mechanisms for services.	*Consider reaching out to the following partners:* ☐ WIC ☐ Family Voices (health insurance concerns) ☐ P2PUSA for emotional support through state Parent-to-Parent organization ☐ Metabolic centers ☐ Medical food vendors Pharmaceutical vendors	**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Jurisdictional public health authority • NBS follow- up coordinator • Healthcare provider(s) • Local pharmacies • Medical food manufacturers • Non-governmental organizations • Emergency management
8.3 **Confirm connection to a long-term follow-up program and services, if applicable.**	☐ As applicable, ensure these efforts and plans are connected to the State CYSHCN and/or long term follow-up program, where such follow-up programs exist.		**State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program **Local:** • Healthcare provider(s) • NBS follow- up coordinator • Laboratory(ies) • Families

Strategic Objective 9 Perform other activities determined appropriate by the HHS Secretary.			
Objectives	**Are the following activities/plans in place?**	**Resources / Tips**	**Responsible Entities**
9.1 Identify and address preparedness issues for the NBS systems.	☐ 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 families about the need for individualized emergency response plans. ☐ Search the NBS contingency plan for instructions to "activate" various mechanisms and make sure those mechanisms have already been established and are in place. ☐ Develop and follow a plan to periodically hold drills or practice the NBS contingency plan. ☐ Establish communications with 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.		**Federal:** • HHS **State:** • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Hospital Preparedness Director • State Emergency Management Director or designee **Local:** • Jurisdictional public health authority • NBS program • Hospital Incident Command staff • Birthing facilities • Laboratory(ies) • Local Emergency Management
9.2 Implement, maintain and validate the NBS Contingency Plan			**Federal:** • HHS

Appendix B. Model Memorandum of Understanding/Agreement (MOU/MOA)

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 that 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 ____ weeks of 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 service s. 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 agree 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 his/her 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 ____ 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 ____ days advance written notice. This MOU shall not be altered, changed, modified, or amended except by written consent of all parties to the MOU.

Signatories

The signatories of this Memorandum of Understanding will be responsible for activating this MOU whenever a disaster occurs in the Public Health Laboratory operation.

For their respective State Laboratories:

_____ _____

Laboratory Director Laboratory Director

Date: _____ Date: _____

For the State Agencies:

_____ _____

Commissioner Department of Health Commissioner Department of Health

Date: _____ Date: _____

Appendix C. Additional Resources

This appendix contains resources, templates, case studies, state examples and other information that may be helpful to states developing, updating, and/or implementing their NBS contingency plans. This list is neither comprehensive nor exhaustive.

Background Resources

- Disaster Preparedness: Pediatric Tabletop Exercise Resource Kit: https://www.aap.org/en/patient-care/disasters-and-children/pediatric-tabletop-exercise-resource-kit/
- Overview of Emergency Management Assistance Compact (EMAC): https://www.fema.gov/pdf/emergency/nrf/EMACoverviewForNRF.pdf
- EMAC's 13 Articles: https://www.leg.state.nv.us/nrs/NRS-415.html
- Emergency Preparedness for Children with Special Health Care Needs. (Website) American Academy of Pediatrics. Available from: Emergency Preparedness for Children with Special Health Care Needs
- Emergency Preparedness Requirements for Medicare and Medicaid Participating Providers and Suppliers (CMS EP Rule): https://asprtracie.hhs.gov/cmsrule
- Hurricane Resources at Your Fingertips: https://files.asprtracie.hhs.gov/documents/aspr-tracie-hurricane-resources-at-your-fingertips.pdf
- NewSTEPs COVID-19 NBS response: Education and Outreach. Available from: https://www.newsteps.org/resource-library/covid-19-nbs-response-education-and-outreach?q=resources/covid-19-nbs-response-education-and-outreach.
- Public Health Preparedness Tools. (Website)Agency for Healthcare Research and Quality, U.S. Dept. of Health and Human Services. Available from: https://asprtracie.hhs.gov/technical-resources/resource/3190/public-health-emncy-preparedness-archive-tools-and-resources.
- Women, Infants and Children (WIC) Detailed Policy Guidance in Disaster Situations. Available from: https://catalog.data.gov/dataset/women-infants-and-children-wic-detailed-policy-guidance-in-disaster-situations

Case Examples

- Lessons Learned: Maintaining Operations for a Two-screen Newborn Screening Program Through a Full Laboratory Building Shutdown. Hanley G. APHL 2023 Newborn Screening Symposium presentation. Available from: https://vimeo.com/894513465?share=copy
- The Iowa COOP CQI Project: Developing, Testing and Implementing a COOP Communications Plan. Johnson C. APHL 2023 Newborn Screening Symposium presentation. Available from: https://vimeo.com/894513465?share=copy
- Improving COOP in South Carolina: Lessons Learned from Memorial Day Weekend 2021. APHL 2022 Newborn Screening Symposium presentation. Bair E. Available from: https://vimeo.com/787690946

- Genetic/metabolic health care delivery during and after hurricanes Katrina and Rita - Andersson HC, Narumanchi TC, Cunningham A, Bowdish B, Thoene J. Available from: https://pubmed.ncbi.nlm.nih.gov/16311054/
- New Jersey Prioritizes Newborn Screening Program in the Face of Hurricane Sandy. Association of State & Territorial Health Officials. Available from: https://www.newsteps.org/sites/default/files/2020-10/HYS%20NJ%20Sandy%20Newborn%20Screen%20FINAL%2020131007%20%281%29.pdf.
- "Lab technician braves blizzard for results that save newborn's life" (2015, WCBV. com) – news story highlighting importance of contingency planning during a blizzard in Massachusetts: https://www.wcvb.com/article/lab-technician-braves-blizzard-for-results-that-save-newborn-s-life/8219146.

Appendix D. References

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Appendix E. Acronyms

ABR..... Auditory Brainstem Response

ACHDNC .... Advisory Committee on Heritable Disorders in Newborns and Children

AMCHP ..... Association of Maternal & Child Health Programs

APHL..... Association of Public Health Laboratories

ATSDR.....Agency for Toxic Substances and Disease Registry

CCHD ..... Critical Congenital Heart Disease

CDC..... U.S. Centers for Disease Control and Prevention

CLIA ..... Clinical Laboratory Improvement Amendments

COOP ..... Continuity of Operations Plan

CONPLAN... Contingency Plan

CYSHCN ..... Children and Youth with Special Health Care Needs

DBS ..... Dried Blood Spot

DCIRs ..... Director's Critical Information Requirements (CDC)

DSCSHN ..... Division of Services for Children with Special Health Needs (HRSA)

EHDI..... Early Hearing Detection and Intervention

EMAC..... Emergency Management Assistance Compact

HHS..... U.S. Department of Health and Human Services

HIPAA..... Health Insurance Portability and Accountability Act

HITECH ..... Health Information Technology for Economic and Clinical Health Act

HRSA..... Health Resources and Services Administration

MCHB..... Maternal and Child Health Bureau

MOA..... Memorandum of Agreement

MOU..... Memorandum of Understanding

NBS..... Newborn Screening

NCEH.....National Center for Environmental Health

NCBDDD.... National Center on Birth Defects and Developmental Disabilities

NDMS..... National Disaster Medical System

NSQAP .....Newborn Screening Quality Assurance Program (CDC)

RUSP..... Recommended Uniform Screening Panel

OAE..... Otoacoustic Emissions

ORR.....Office of Readiness and Response

OTASA .....Office of Tribal Affairs and Strategic Alliances

POC ..... Point-of-care

SOP..... Standard Operating Procedure

U.S. ..... United States

WIC..... Women, Infants & Children

Appendix F. CONPLAN Update Advisory Committee Members, 2023 – 2024

Advisory Committee Members

Sabra Anckner RN, MSN
Associate Director, Clinical & Community Collaboration, Association of Maternal and Child Health Programs

Elizabeth Baird, MS
Chemistry Division Director, South Carolina Department of Health and Environmental Control

Amy Brower, PhD
Director – Long-Term Follow-Up Cares and Check Initiative, American College of Medical Genetics and Genomics

M. Christine Dorley, PhD | Chair
Assistant Director, Newborn Screening Laboratory, Tennessee Department of Health, Laboratory Services

Roger Eaton, PhD
Director, New England Newborn Screening Program

Debra Freedenberg, MD, PhD
Organizational Representative, American Academy of Pediatrics (AAP), Medical Geneticist

Marcus Gaffney, MPH
Lead Health Scientist, Newborn Screening & Molecular Biology Branch, Division of Laboratory Sciences, National Center for Environmental Health, Centers for Disease Control and Prevention

Patrice Held, PhD FACMG
Newborn Screening Program Manager, Oregon State Public Health Laboratory

Cynthia Hinton, PhD, MS, MPH
Health Scientist, Newborn Screening and Molecular Biology Branch, National Center on Environmental Health, Centers for Disease Control and Prevention

Christine Mackie, MPH
Vice President, Community Health and Prevention Association of State and Territorial Health Officials

Joyal Meyer RN, MSN
North Dakota Newborn Screening Program Director, Division of Special Health Services

Alisha Keehn, MPA
Branch Chief, Genetic Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

Kim Morrison, MS
Public Health Analyst, Genetic Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

Jelili Ojodu, MPH
Director, Newborn Screening and Genetics Program Association of Public Health Laboratories (APHL)

Kimberly Piper, RN, BS, CPH, CPHG
Director, Center for Congenital and Inherited Disorders, Division of Public Health, Iowa Department of Health and Human Services

Ellen Pliska, MHS, CPH
Family and Child Health Senior Director, Community Health and Prevention, Association of State and Territorial Health Officials

Marianna Raia MS, CGC
Associate Director of Programs, Expecting Health

Alyson Saadi, MNS, MB (ASCP)
Associate Director – Clinical, Louisiana Department of Health – Office of Public Health Laboratory

Scott Shone, PhD, HCLD(ABB)
Laboratory Director, Division of Public Health, North Carolina State Laboratory of Public Health

Guisou Zarbalian, MS, MPH
Manager, Newborn Screening and Genetics Program Association of Public Health Laboratories (APHL)