

These are printable checklists and Memorandum of Understanding for use with *Newborn Screening Contingency Plan Version 3*.

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
<p>1.1 Establish an effective NBS communication network that connects families, providers, birth facilities, and agency staff.</p>	<p>External Communications: Establish relationships with and identify contact information for/established relationships with the following:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Birth facilities – nursery and laboratory <input type="checkbox"/> Known midwives <input type="checkbox"/> Local family practice and pediatrician groups <input type="checkbox"/> Appropriate specialists <input type="checkbox"/> Families already identified with a newborn screening condition <p>Employ multiple communication modalities:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Phone: <ul style="list-style-type: none"> <input type="checkbox"/> Emergency call-back systems <input type="checkbox"/> Integrate with Health Alert Network <input type="checkbox"/> Social Media (Facebook, Twitter) <input type="checkbox"/> Text <input type="checkbox"/> Email <input type="checkbox"/> Family resource centers (e.g., state Family to Family Health Information Center, Family Voices, Genetic Alliance) <input type="checkbox"/> Radio & Television <input type="checkbox"/> Program/Agency <input type="checkbox"/> Website updates <input type="checkbox"/> Streaming audio sessions <p>Provide education and training on state newborn screening practices to the following:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Families <input type="checkbox"/> Providers <input type="checkbox"/> Birthing facilities/midwifery practices <input type="checkbox"/> 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. <ul style="list-style-type: none"> <input type="checkbox"/> Incorporate emergency processes into standard communications to NBS system partners 	<ul style="list-style-type: none"> <input type="checkbox"/> Ensure all NBS system partners are aware of the existence of a contingency plan. <input type="checkbox"/> Consider social media as an internal communication mechanism. <input type="checkbox"/> For websites, consider a designated area or state communication portal for emergency information. 	<p>State:</p> <ul style="list-style-type: none"> • 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 <p>Local:</p> <ul style="list-style-type: none"> • 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
	<p>Internal Communications:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Define a call-back system for in-house staff and NBS system partners. <input type="checkbox"/> Review and update the system at least semiannually. <input type="checkbox"/> Store critical data needed for activation of the COOP at an off-site location (or location accessible remotely) for ready access. <input type="checkbox"/> 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. <input type="checkbox"/> Store any relevant standard operating procedures needed to carry out COOP activities on a secure site available remotely. 		
<p>1.2 Establish emergency plan to communicate with network in a crisis.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Determine which types of emergency will require emergency communications and to whom. <input type="checkbox"/> Create centralized communication hotline for newborn screening. <input type="checkbox"/> Educate NBS system partners on how they will receive information about newborn screening in an emergency. <input type="checkbox"/> Incorporate the National Standards for Culturally and Linguistically Appropriate Services (CLAS) into preparedness activities: <ul style="list-style-type: none"> <input type="checkbox"/> Perform needs assessment and gap analysis. Develop key messages in appropriate languages in advance of emergency situations. <input type="checkbox"/> 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. 	<p>Consider developing a specific communication plan and channels with alternative/ back-up screening entities.</p> <p>Other situations or points to consider:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Personnel shortages (e.g., strikes) <input type="checkbox"/> Consider cross-training <input type="checkbox"/> Loss of supplies (NBS kits) <input type="checkbox"/> Hospital evacuation <input type="checkbox"/> Electronic medical records system (EMR) goes down 	<p>State:</p> <ul style="list-style-type: none"> • 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 <p>Local:</p> <ul style="list-style-type: none"> • 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
			<ul style="list-style-type: none"> • NBS program • Hospital Incident Command Staff • Birthing Facilities • Laboratory(ies) • Local Emergency Management
<p>1.3 Ensure multiple communication modalities are in place and are being utilized.</p>	<p>Establish a variety of communication modalities, including:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Agency email listserv <input type="checkbox"/> Organizational listservs (e.g., APHL, AAP, etc.) <input type="checkbox"/> Phone hotline (e.g., Health Alert Network or State HAN Coordinator) <input type="checkbox"/> Social media (Facebook, Twitter) <input type="checkbox"/> Text <input type="checkbox"/> Family support groups and community networks <input type="checkbox"/> Program/Agency Website <input type="checkbox"/> Fax 	<p>Maintaining email and/or contact lists can be challenging:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Use a hotline <input type="checkbox"/> Establish a master contact list and update it periodically <p>Social media venues to consider could include:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Agency/Program <input type="checkbox"/> External partner organizations (Expecting Health, APHL, family support groups, etc.) 	<p>State:</p> <ul style="list-style-type: none"> • 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 <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional public health authority

Strategic Objective 2

Educate families about NBS.

Objectives	Are the following activities/plans in place?	Resources / Tips	Responsible Entities
<p>2.1 Ensure families know about the need for NBS, when and how it is conducted.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Identify pregnant women and families with newborn babies. <input type="checkbox"/> Deliver information about NBS at the time the specimen is obtained or point-of-care screening is performed. <input type="checkbox"/> Ensure families understand the information. <input type="checkbox"/> Raise awareness of the public health functions of the state NBS program. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/CYSHCN program • State Hospital Preparedness Director <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional public health authority • Birthing or screening facility. • NBS program • Families
<p>2.2 Ensure families know how to obtain NBS results.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Provide families with information and education on how to obtain screening results. <input type="checkbox"/> Include state emergency agencies' contact information in documents and information distributed to families. <input type="checkbox"/> Request alternate/emergency contact information for family on the NBS specimen kit. <input type="checkbox"/> 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. <input type="checkbox"/> 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. <input type="checkbox"/> If a newborn fails a hearing screen, families should receive results and follow-up appointment information. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • State Title V MCH/CYSHCN program • State Hospital Preparedness Director <p>Local:</p> <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> <input type="checkbox"/> Provide families information about access to care. <input type="checkbox"/> Provide families with information on the potential meaning of a positive or out-of-range result and need for confirmatory testing for diagnostic purposes. <input type="checkbox"/> If testing confirms a diagnosis, provide information on short-term follow-up and linkage to specialty care. 		State: <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • State Title V MCH/CYSHCN program • State Hospital Preparedness Director Local: <ul style="list-style-type: none"> • 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.	<ul style="list-style-type: none"> <input type="checkbox"/> Contact the Association of Public Health Laboratories (APHL) to request emergency blood spot collection cards from CDC's NSQAP. <input type="checkbox"/> Ensure cards are not expired. <input type="checkbox"/> Facilitate redistribution of locally available cards until supplies are exhausted. <input type="checkbox"/> Notify and activate national repository to deliver cards in anticipation of local supplies being depleted. <input type="checkbox"/> Facilitate distribution of cards to jurisdiction. <input type="checkbox"/> Facilitate distribution of cards to collection points. 		State: <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State Hospital Preparedness Director Local: <ul style="list-style-type: none"> • 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
<p>3.2 Ensure that other materials necessary for DBS collection, hearing and pulse oximetry CCHD screens are available.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Ensure availability of materials required for blood spot collection, including lancets, alcohol pads, and packaging at hospitals and other potential collection sites. <input type="checkbox"/> 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. <input type="checkbox"/> Ensure availability of materials for hearing screening, such as OAE and ABR screening equipment and necessary supplies (e.g., probes). 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • State Hospital Preparedness Director <p>Local: Hospitals and other potential collection and screening sites</p>
<p>3.3 Ensure that training materials and SOPs on conducting DBS and POC screening, and collection of specimens are available.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Train medical professionals who may be involved in dried blood spot collection. <input type="checkbox"/> 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. <input type="checkbox"/> Collect appropriate specimens and conduct appropriate point-of-care screens. <input type="checkbox"/> Record accurate demographics and results of point-of-care screenings (to allow complete screening, including follow-up testing). <input type="checkbox"/> Maintain a log of all dried blood spot specimens collected or refused at the collection site. <input type="checkbox"/> 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. <input type="checkbox"/> Forward completed and dried blood spot specimen to shipping location. <input type="checkbox"/> Report CCHD and hearing screening results to appropriate state program. <input type="checkbox"/> 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. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • State Preparedness Director • NBS Program Director • State EHDI Coordinator • State Hospital Preparedness Coordinator <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>4.1 Provide SOPs and training on shipping specimens.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Assess the situation and the operational status of laboratories and transport system. <input type="checkbox"/> 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. <input type="checkbox"/> Train medical professionals who may be involved in dried blood spot specimen transport. <input type="checkbox"/> Ship to primary laboratory, if available. Ship to secondary or tertiary laboratories when necessary. <input type="checkbox"/> Operationalize tracking system to document chain of custody of specimens. <input type="checkbox"/> Maintain a log of all dried blood spot specimens packaged and transported. <input type="checkbox"/> Notify courier of any special pick-up or delivery issues (e.g., timing, or location). 	<p>Weather-related impacts to transportation routes or courier strikes may present the need to consider alternate couriers:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Consider local and state public entities, such as the National Guard, local police and fire personnel, the State Highway Patrol, and Sheriff's Department as potential alternative couriers. 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State Preparedness Director • State Hospital Preparedness Director <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional health official • NBS Program Coordinator(s) • Public Health and Hospital Preparedness Coordinators • Hospital and other potential collection facilities • Laboratory(ies) • Local Emergency Management
<p>4.2 Have an emergency plan in place and alternative laboratories selected, should specimens need to be redirected.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Notify courier of any special pick-up or delivery issues, if not already done. <input type="checkbox"/> Contact transport system provider and execute change of address. 	<ul style="list-style-type: none"> <input type="checkbox"/> Consider centralized courier pick-up site. 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • Courier services <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>4.3 Have a system to alert for missing or not-shipped specimens, so they can be re-collected quickly.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Identify missing specimen(s). <input type="checkbox"/> Contact the newborn’s provider and birth hospital. <input type="checkbox"/> Locate the newborn and newborn’s family. Collect a second specimen. <input type="checkbox"/> Use Public Service Announcements (PSAs) to aid in advising parents of newborns affected by an emergency incident when necessary. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State Hospital Preparedness Director <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>5.1 Assess laboratory capability and capacity.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Assess facilities, supplies, reagents, utilities, staff, informatics, supply chain, transport systems, safety issues or working environment, and communication systems. <input type="checkbox"/> Assess potential duration of interruption and disruption of lab capacity or service. <input type="checkbox"/> Document assessment. 	<p><i>Situations you may want to consider:</i></p> <p>Shortage of reagents or other laboratory supplies or materials</p> <p>Power outage:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Have back-up power (batteries, generator) on-hand <input type="checkbox"/> Be on priority list with power company <p>Breakage of laboratory equipment, machinery or technology:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Examine maintenance contracts <p>Personnel shortage (illness, inability to get into office, reassigned or detailed elsewhere):</p> <ul style="list-style-type: none"> <input type="checkbox"/> ID essential personnel <input type="checkbox"/> Provide letter/ card to identify essential personnel <input type="checkbox"/> Identify back-up staff <input type="checkbox"/> Identify emergency transportation assets 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State Preparedness Director • State Hospital Preparedness Director <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>5.2 Ensure integrity of specimens and records, especially if sent to a back-up laboratory.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Evaluate potential risk to specimens and records. <input type="checkbox"/> Take appropriate actions to ensure integrity of specimens and records. <input type="checkbox"/> Make a record of damaged or compromised specimens and records. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • Back-up laboratory(ies) <p>Local:</p> <ul style="list-style-type: none"> • Hospitals and other potential collection facilities • Laboratory (ies) • NBS program staff • Health care providers
<p>5.3 Address emergency situations to preserve or restore capacity.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Contact vendors, tech support, facilities, and maintenance to determine if emergency repair support is available. <input type="checkbox"/> Estimate time required to complete repairs. <input type="checkbox"/> Initiate repairs as feasible. <input type="checkbox"/> Maintain record of any repairs made. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management
<p>5.4 Decide whether additional or alternative capacity is needed.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Make a timely judgment whether existing resources are sufficient or if a back-up lab is needed. <input type="checkbox"/> Identify the appropriate resources that are needed to achieve capacity. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>5.5 If additional capacity is needed, seek assistance or activate back-up plan.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Contact APHL and NewSTEPS. <input type="checkbox"/> Contact State Emergency Manager with recommendations on the need to activate EMAC, if applicable. <input type="checkbox"/> Identify and contact back-up laboratory. <input type="checkbox"/> Ensure that the back-up laboratory is CLIA-approved and participates in the CDC NSQAP. <input type="checkbox"/> Establish disorder panel needs. <input type="checkbox"/> Identify and address or resolve major algorithm, information technology (IT), and methodological or protocol differences. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management
<p>5.6 Notify appropriate internal and external NBS system partners (including personnel) of the change in process during an emergency.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Notify personnel according to internal procedures. <input type="checkbox"/> Notify external NBS system partners, State Health Officer, State Title V CYSHCN Director, providers and sub-specialists, and the public, as needed. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • Hospitals and other potential collection facilities • Laboratory (ies) • Courier services • Local Emergency Management
<p>5.7 Maintain a record of all dried blood spot specimens sent to and received by the back-up laboratory.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> All entities submitting specimens keep a log of specimens submitted. <input type="checkbox"/> All entities receiving specimens keep a log of specimens received. <input type="checkbox"/> When possible and as feasible, compare records of transported specimens. Identify missing specimens. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • 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.	<input type="checkbox"/> Back-up laboratories sort external specimens.		State: <ul style="list-style-type: none"> • State Health Official • NBS Program Director Local: <ul style="list-style-type: none"> • Back-up laboratory(ies)
5.9 Specimens are analyzed and results are reported.	<input type="checkbox"/> Analyze specimens. <input type="checkbox"/> Report results to submitters. <input type="checkbox"/> Report the positive results to the follow-up system. <input type="checkbox"/> Unsatisfactory and out-of-range are reported to appropriate follow-up system. <input type="checkbox"/> Request second specimen, if needed. <input type="checkbox"/> Return specimen to originating state.		State: <ul style="list-style-type: none"> • State Health Official • NBS Program Director Local: <ul style="list-style-type: none"> • 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
<p>6.1 Establish communication lines between the sending and receiving laboratories, hospitals, and NBS follow-up coordinator(s).</p>	<input type="checkbox"/> Assess options for communication among laboratories, hospitals performing CCHD and hearing screenings, and NBS follow-up coordinator. <input type="checkbox"/> Formulate communication strategy. <input type="checkbox"/> Implement strategies for communication.	<p><i>To address variability in reporting, consider:</i></p> <input type="checkbox"/> Discussing data definitions, reporting verbiage and interpretations within communications strategy. <p><i>If database for laboratory is unavailable, consider:</i></p> <input type="checkbox"/> Developing alternate method to report results to short-term follow-up and health care providers.	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Emergency management <p>Local:</p> <ul style="list-style-type: none"> • NBS program • Healthcare provider • NBS follow- up coordinator • Families • Emergency management
<p>6.2 Establish communication lines between the NBS follow-up program and healthcare provider; if unavailable, communicate directly with families.</p>	<input type="checkbox"/> Determine if newborn screening card submitter or physician of record is available. <input type="checkbox"/> Identify alternative provider to report results, if needed. Report results to submitter or physician of record or alternative provider. <input type="checkbox"/> Healthcare provider confirms to NBS coordinator that newborn is in care. <p>If healthcare provider is not available:</p> <input type="checkbox"/> Locate family. <input type="checkbox"/> Inform family of newborn screening results and need for additional care. <input type="checkbox"/> Link family to healthcare provider, ultimately a primary care provider/medical home.	<p><i>If contact numbers for healthcare providers and specialists are electronic only:</i></p> <input type="checkbox"/> Develop and maintain alternate method to store contact information for healthcare providers and sub-specialists	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Emergency management <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>6.3 Track all screening specimens and results.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Develop a registry of specimens collected, and hearing and CCHD screens performed or refused. <input type="checkbox"/> Record all results – positive or out-of-range, borderline, and negative or within normal limits – in registry. <input type="checkbox"/> Resolve all open newborn screening follow-up cases. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • Hospitals and other potential collection and screening sites • Health care providers • NBS follow- up coordinator
<p>6.4 Identify newborns who are not screened.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Match screening records with birth records to identify newborns not screened. <input type="checkbox"/> Contact families of newborns who did not receive NBS. 	<p><i>Depending on the emergency event and systems impacted, obtaining birth records may be difficult. Consider:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> Documenting alternative approaches in advance. <p><i>To contact families, consider:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> 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 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional Health Official • NBS program • Laboratory(ies) • Local Emergency Management

		screened and valid results were obtained. <input type="checkbox"/> Consider PSAs in your state and surrounding states to which residents may have relocated.	
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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
<p>7.1 After an out-of-range screen, ensure diagnostic testing is performed and tracked.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Healthcare provider consults with appropriate sub-specialist. <input type="checkbox"/> Healthcare provider identifies indicated diagnostic test(s) and laboratories. <input type="checkbox"/> 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. <input type="checkbox"/> Collect and send samples to diagnostic laboratories. <input type="checkbox"/> 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. <input type="checkbox"/> Report diagnostic test results to appropriate healthcare professionals, sub-specialists, designated state programs, or sample submitters as applicable. 	<ul style="list-style-type: none"> <input type="checkbox"/> 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. <input type="checkbox"/> If getting to follow-up care is difficult for families, consider telehealth options, if available. 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • Hospitals and other potential collection and screening sites • Health care providers • NBS follow-up coordinator
<p>7.2 Establish a diagnosis and communicate results to the healthcare provider, family, and NBS program.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Healthcare provider and sub-specialist confer regarding diagnostic test results and establish diagnosis, as appropriate. <input type="checkbox"/> Identify and conduct additional diagnostic evaluations, as appropriate. <input type="checkbox"/> Communicate results to family. <input type="checkbox"/> Notify NBS program of results and diagnosis. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>8.1 Identify appropriate treatment, services, and/or interventions.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Identify a primary care provider and specialist(s). <input type="checkbox"/> Appropriate healthcare provider and sub-specialist confer and discuss treatment recommendations and services and discuss with family. <input type="checkbox"/> Provide acute or urgent care, if needed. <input type="checkbox"/> Ensure newborns identified with hearing loss are referred to the state early intervention (Part C) program. <input type="checkbox"/> Confirm each child’s access to and connection with a medical home, as applicable. 	<ul style="list-style-type: none"> <input type="checkbox"/> 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. <input type="checkbox"/> 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. <input type="checkbox"/> Consider telehealth options as needed, if available. 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>8.2 Confirm access to and connection with a medical home for delivery of appropriate multidisciplinary services.</p>	<p>As applicable,</p> <ul style="list-style-type: none"> <input type="checkbox"/> Establish a mechanism to track affected displaced populations. <input type="checkbox"/> Initiate chronic condition management. <input type="checkbox"/> Initiate care coordination between primary care provider and specialist(s). <input type="checkbox"/> 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. <input type="checkbox"/> Develop a treatment plan. <input type="checkbox"/> Facilitate access to counseling and social services. <input type="checkbox"/> Facilitate access to medical foods, pharmaceuticals, and devices. <input type="checkbox"/> Establish reimbursement mechanisms for services. 	<p><i>Consider reaching out to the following partners:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> WIC <input type="checkbox"/> Family Voices (health insurance concerns) <input type="checkbox"/> P2PUSA for emotional support through state Parent-to-Parent organization <input type="checkbox"/> Metabolic centers <input type="checkbox"/> Medical food vendors <input type="checkbox"/> Pharmaceutical vendors 	<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional public health authority • NBS follow-up coordinator • Healthcare provider(s) • Local pharmacies • Medical food manufacturers • Non-governmental organizations • Emergency management
<p>8.3 Confirm connection to a long-term follow-up program and services, if applicable.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> 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. 		<p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program <p>Local:</p> <ul style="list-style-type: none"> • 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
<p>9.1 Identify and address preparedness issues for the NBS systems.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Establish and maintain a national blood spot collection card repository communication strategy. <input type="checkbox"/> Establish contingency plans for transfer of care (for affected individuals) from one health care system to another. <input type="checkbox"/> Educate families about the need for individualized emergency response plans. <input type="checkbox"/> Search the NBS contingency plan for instructions to “activate” various mechanisms and make sure those mechanisms have already been established and are in place. <input type="checkbox"/> Develop and follow a plan to periodically hold drills or practice the NBS contingency plan. <input type="checkbox"/> Establish communications with state EMAC (i.e., each NBS program should establish these communication channels). <input type="checkbox"/> Assess the NBS emergency operations plans that states have developed and maintain an electronic library of such documents. <input type="checkbox"/> Develop the mechanism or ability to assist with information, data, or results management among states for NBS systems. <input type="checkbox"/> Establish relationships (among jurisdictions) related to mutual aid for NBS systems. 		<p>Federal:</p> <ul style="list-style-type: none"> • HHS <p>State:</p> <ul style="list-style-type: none"> • State Health Official • NBS Program Director • State EHDI Coordinator • Title V MCH/ CYSHCN program • Hospital Preparedness Director • State Emergency Management Director or designee <p>Local:</p> <ul style="list-style-type: none"> • Jurisdictional public health authority • NBS program • Hospital Incident Command staff • Birthing facilities • Laboratory(ies) • Local Emergency Management
<p>9.2 Implement, maintain and validate the NBS Contingency Plan</p>			<p>Federal:</p> <ul style="list-style-type: none"> • 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 services. Assigned employees will comply with rules and regulations of the support laboratory.

Funding

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

Transportation and Delivery of Specimens or Samples

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

Chain of Custody

All samples or specimens and physical evidence received under chain of custody will be maintained under secure conditions during storage, testing, and retention of evidence until the case is resolved. Laboratory staff involved in receipt of samples or specimens, or storage and testing 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
Date: _____

Laboratory Director
Date: _____

For the State Agencies:

Commissioner Department of Health
Date: _____

Commissioner Department of Health
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

117th Congress (2021-2022). H.R.482 – Newborn Screening Saves Lives Reauthorization Act of 2021. Available from: <https://www.congress.gov/bill/117th-congress/house-bill/482/text>

Advisory Committee on Heritable Disorders in Newborns and Children’s Recommendations on Timely Newborn Screening Goals, 2015. Available from: <https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/meetings/letter-sec-timely-newborn.pdf>.

An Overview of Legal Considerations in Assessing Multijurisdictional Sharing of Public Health Laboratory Testing Services; Association of Public Health Laboratories, CDC Office for State, Tribal, Local and Territorial Support, CDC Office of Surveillance, Epidemiology and Laboratory Services, Public Health Law Program, and Laboratory Efficiencies Initiative (2012). Available from: <https://stacks.cdc.gov/view/cdc/25549>.

Andersson HC, Narumanchi TC, Cunningham A, Bowdish B, Thoene J. Genetic/metabolic health care delivery during and after hurricanes Katrina and Rita. *Mol Genet Metab.* 2006;88(1):3-6. doi:10.1016/j.ymgme.2005.10.002

Andersson HC, Perry W, Bowdish B, Floyd-Browning P; Southeast Region Genetics Collaborative. Emergency preparedness for genetics centers, laboratories, and patients: the Southeast Region Genetics Collaborative strategic plan. *Genet Med.* 2011;13(10):903-907. doi:10.1097/GIM.0b013e31821fea08

Emergency Preparedness for Laboratory Personnel resources from CDC Emergency Preparedness and Response. Available from: <https://emergency.cdc.gov/labissues/index.asp>

Emergency Preparedness for Newborn Screening and Genetic Services, American College of Medical Geneticists (2009). Available from: <https://www.acmg.net/PDFLibrary/Emergency-Preparedness-NBS.pdf>

Floyd-Browning P, Perry W, Andersson HC; Southeast Regional Collaborative Emergency Preparedness Workgroup. Newborn screening: a national snapshot with implications for emergency preparedness. *J Pediatr.* 2013;162(5):955-7.e1-2. doi:10.1016/j.jpeds.2012.10.058

Gaviglio A, McKasson S, Singh S, Ojodu J. Infants with Congenital Diseases Identified through Newborn Screening-United States, 2018-2020. *Int J Neonatal Screen.* 2023;9(2):23. Published 2023 Apr 13. doi:10.3390/ijns9020023

Guidelines for the Public Health Laboratory Continuity of Operations Plan, Association of Public Health Laboratories (APHL). Available from: https://www.aphl.org/programs/preparedness/Documents/PHPR_2011Feb_PHL-Continuity-of-Operations-Guidelines.pdf.

Joint Committee on Infant Hearing. Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics* 2007;120:898–921.

Kemper AR, Mahle WT, Martin GR, Cooley WC, Kumar P, Morrow WR, et al. Strategies for implementing screening for critical congenital heart disease. *Pediatrics.* 2011;128(5):e1259-1267.

Oregon Newborn Bloodspot Screening Practitioner’s Manual 12th Edition, 2022. Available from: <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le8189.pdf>

Pass KA, Lane PA, Fernhoff PM, et al. US newborn screening system guidelines II: follow-up of children, diagnosis, management, and evaluation. Statement of the Council of Regional Networks for Genetic Services (CORN). *J Pediatr.* 2000;137(4 Suppl):S1-S46. doi:10.1067/mpd.2000.109437

Policy Guide for Public Health Laboratory Test Service Sharing; Association of Public Health Laboratories, Laboratory Efficiencies Initiative (2014). Available from:
https://www.aphl.org/aboutaphl/publications/documents/lei-policy-guide_april2014.pdf.

SIMD Position Statement: Identifying abnormal newborn screens requiring immediate notification of the health care provider, 2014. Society for Inherited Metabolic Disorders. Available from:
<https://metabodabble.org/SIMD/Statements/SIMD%20NBS%20Critical%20Conditions%20policy%20statement.pdf>.

Singh S, Caggana M, Johnson C, Lee R, Zarbalian G, Gaviglio A, Keehn A, Morrison M, Becker SJ, Ojodu J. COVID-19 Pandemic-Related Impacts on Newborn Screening Public Health Surveillance. *International Journal of Neonatal Screening*. 2022; 8(2):28. <https://doi.org/10.3390/ijns8020028>

Watson MS, Mann MY, Lloyd-Puryear MA, Rinaldo P, Howell RR. Newborn Screening: Toward a Uniform Screening Panel and System—Executive Summary. *Pediatrics*. 2006;117:S296-S307.
https://publications.aap.org/pediatrics/article/117/Supplement_3/S296/68871/Newborn-Screening-Toward-a-Uniform-Screening-Panel?searchresult=1?autologincheck=redirected

Appendix E. Acronyms

ABR.....	Auditory Brainstem Response	MCHB	Maternal and Child Health Bureau
ACHDNC	Advisory Committee on Heritable Disorders in Newborns and Children	MOA	Memorandum of Agreement
AMCHP.....	Association of Maternal & Child Health Programs	MOU.....	Memorandum of Understanding
APHL	Association of Public Health Laboratories	NBS.....	Newborn Screening
ATSDR.....	Agency for Toxic Substances and Disease Registry	NCEH.....	National Center for Environmental Health
CCHD.....	Critical Congenital Heart Disease	NCBDDD	National Center on Birth Defects and Developmental Disabilities
CDC	U.S. Centers for Disease Control and Prevention	NDMS	National Disaster Medical System
CLIA.....	Clinical Laboratory Improvement Amendments	NSQAP	Newborn Screening Quality Assurance Program (CDC)
COOP.....	Continuity of Operations Plan	RUSP.....	Recommended Uniform Screening Panel
CONPLAN ..	Contingency Plan	OAE.....	Otoacoustic Emissions
CYSHCN	Children and Youth with Special Health Care Needs	ORR.....	Office of Readiness and Response
DBS	Dried Blood Spot	OTASA.....	Office of Tribal Affairs and Strategic Alliances
DCIRs.....	Director's Critical Information Requirements (CDC)	POC.....	Point-of-care
DSCSHN.....	Division of Services for Children with Special Health Needs (HRSA)	SOP.....	Standard Operating Procedure
EHDI	Early Hearing Detection and Intervention	U.S.....	United States
EMAC	Emergency Management Assistance Compact	WIC.....	Women, Infants & Children
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		

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

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