

HHS Child and Adolescent Health Emergency Planning Toolkit

*Guidance for Addressing the Needs of Children
and Youth with Special Health Care Needs*

DESK REFERENCE

January 2023

Background

Purpose

The purpose of this toolkit is to address the needs of children and youth with special health care needs (CYSHCN) and their families/caregivers. This toolkit complements the [HHS Maternal-Child Health Emergency Planning Toolkit](#) as a companion document and aligns with ongoing HHS objectives to ensure health equity for all children, adolescents, and CYSHCN and their families/caregivers across the emergency management cycle.

Providers may use this toolkit to:

- Engage with CYSHCN and their families/caregivers in all aspects of emergency preparedness, response, recovery, mitigation, and community resilience activities.
- Convene providers and partners to identify and address challenges faced by CYSHCN and their families/caregivers in emergencies.
- Prioritize impactful ways to coordinate with state, local, tribal, and territorial (SLTT) emergency management leaders and other partners.
- Create key resources to support emergency planning for CYSHCN and their families/caregivers

Audience

PRIMARY	SECONDARY
<ul style="list-style-type: none">• Health Care Providers (e.g., general pediatric, sub-specialty, school-based, and in-home care teams)• Public Health Officials (e.g., Title V Maternal and Child Health Services Block grantees, Emergency Medical Service for Children State Partners, local and regional emergency planners)¹• Social Services Providers (e.g., social workers, school counselors, child welfare workers)	<ul style="list-style-type: none">• Community-Based Organizations (CBO) (e.g., youth organizations, family-led organizations, faith-based organizations)²• CYSHCN and their families/caregivers• Emergency management agencies

Populations Addressed

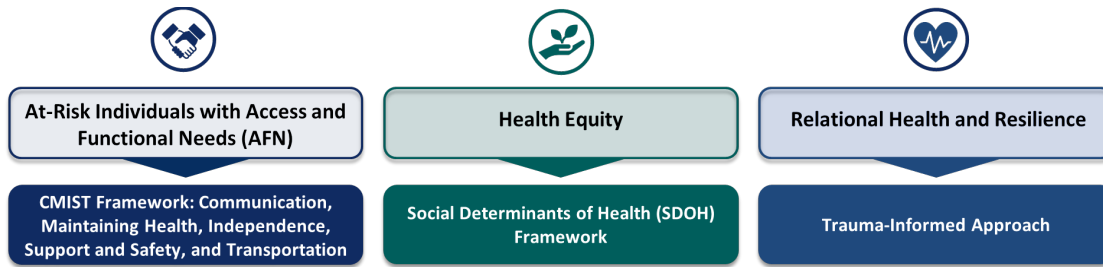
This toolkit focuses on CYSHCN (aged 0-21 years). CYSHCN include those at increased risk for chronic physical, neurological, developmental, behavioral, or emotional conditions who require health and other services beyond those required by children or youth generally. CYSHCN are a heterogeneous population experiencing a diverse set of needs with varying complexity and severity. The definition of CYSHCN is inclusive of children and youth with disabilities, and an important assumption throughout the toolkit is that disability is a natural part of the human experience.

Guiding Concepts and Frameworks

Three complementary frameworks inform and guide this toolkit: the Communication, Maintaining Health, Independence, Support and Safety, and Transportation (CMIST) Framework; the Social Determinants of Health (SDOH) Framework; and the Trauma- Informed Approach.

¹ Emergency planners refer to individuals in the public or private sectors who are responsible for helping communities and organizations anticipate emergencies and conduct emergency planning activities.

² [Community-Based Organizations \(CBOs\)](#) are public or private not-for-profit resource hubs that provide specific services to the community or targeted population within the community. CBOs are trusted entities that know their clients and their communities, want to be engaged, and may have the infrastructure/systems in place to help coordinate emergency activities or serve as a trusted source for information.



Key Strategies: Preparedness

The preparedness phase involves the planning processes, protocols, partnerships, and supplies that will help providers support CYSHCN and their families/caregivers in the event of an emergency. Successful emergency planning is person- and family-centered, includes shared decision-making and respect for youth autonomy in the decision-making process, and promotes equity throughout the emergency management cycle.

Individuals, Families, Caregivers, and Systems of Care

- Utilize person- and family-centered care and shared decision-making models to gain a richer understanding of CYSHCN’s and their family/caregiver’s priorities, needs, and challenges
 - Shared decision-making empowers individuals to make health care decisions about their own well-being with provider guidance and support
 - Support the autonomy of CYSHCN to be a part of the decision-making process
- Recognize that some CYSHCN and their families/caregivers have been marginalized by racism, sexism, classism, ableism, and other forms of oppression that can, in turn, result in distrust towards institutions that have perpetuated inequalities such as government and health care.

Individual Emergency Plan and Kit

- Collaborate with CYSHCN and their families/caregivers to create an emergency plan that considers these different types of threats and hazards, in addition to their specific access and functional needs (AFN), cultural preferences, and personal and community resources.
- Work with CYSHCN and their families/caregivers to:
 - Include information and considerations for emergency response in existing individual plans of care
 - Identify primary and alternate methods for communication
 - Keep contact information for CYSHCN and their families/caregivers, friends, school, and their system of care providers up to date
 - Gather medical records and health information for CYSHCN and ensure they are accurate, up-to-date, and readily accessible in an emergency
 - Identify device and technology needs
 - Determine where and how to find trusted, accurate, and plain language information
 - Pre-identify evacuation plans, shelters that can accommodate AFN and health needs, and alternate care settings
 - Screen CYSHCN for behavioral health needs to identify behavioral health, social determinants of health (SDOH), and health equity concerns that may be exacerbated during an emergency
- Work with CYSHCN and their families/caregivers to prepare an emergency kit and support them in procuring certain supplies and medication that may become unavailable, which includes:

- Prescribe additional batteries for DME, devices or prescribe a longer supply of medication to be included in emergency kit by working with insurance companies
- Address specific needs such as gender, religious beliefs, or live-in multigenerational households

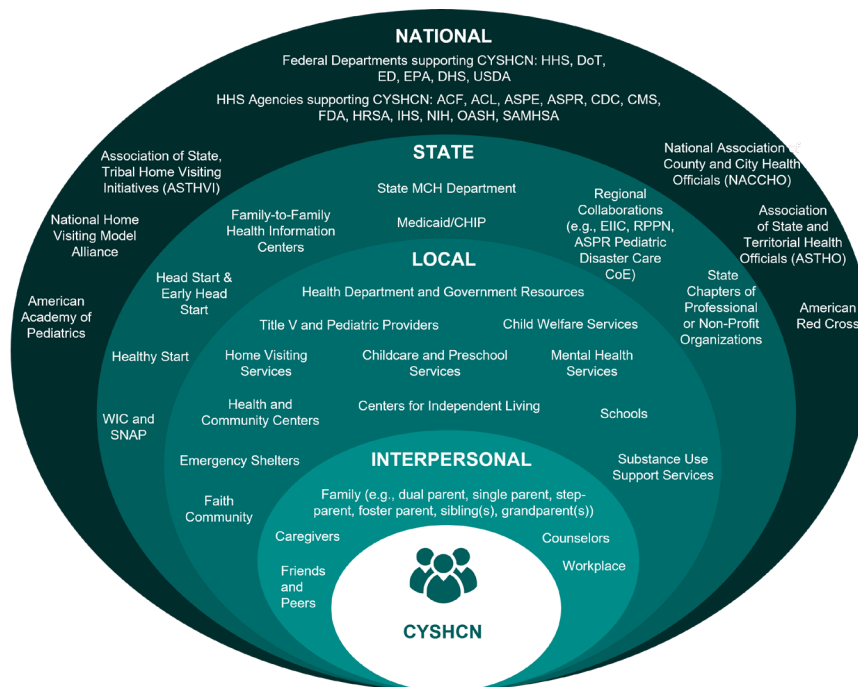
Sample Emergency Kit Items include:

EMERGENCY KIT					
<p>Health Information</p> <ul style="list-style-type: none"> • Copy of shared care plan (paper and/or electronic) and other relevant health documents • Identification to be carried by each family member • Proof of legal guardianship • Extra medical alert bracelets or necklace • Copies of prescription information • Location and phone number for an out-of-town pharmacy 	<p>Medication, Equipment and Devices</p> <ul style="list-style-type: none"> • Extra supply of prescription medicine and medical care items (e.g., needles, nasal cannulas, bandages) • Inhaler spacers • Hearing aids • Medical equipment (e.g., power wheelchair, crutches) • Masking and personal protective equipment (PPE) 	<p>Power and Related Supplies</p> <ul style="list-style-type: none"> • Battery-powered or other backup versions of medical equipment (e.g., manual wheelchair, walking aids) • Extra batteries • Backup chargers for phone and laptop • AC adaptor to charge small electrical equipment (e.g., nebulizer) • Flashlights 	<p>First Aid Kit</p> <ul style="list-style-type: none"> • Antibiotic ointments • Band-aids • Age-appropriate over-the-counter pain relievers 	<p>Food and Water</p> <ul style="list-style-type: none"> • Non-perishable food • Special dietary foods and supplies (e.g., formula, electrolyte replacement fluids) • Culturally appropriate foods • Water in adequate quantity • Blender 	<p>Personal Items</p> <ul style="list-style-type: none"> • Cash • Basic clothing items for each individual • Basic hygiene items • Menstrual products • Seasonal items (e.g., blanket, warm coat, snow boots, umbrella, hat, sunscreen) • Braille kits • Sensory tools • Noise cancelling headphones

Partnerships and Coordination

- Take the time to build relationships and work collaboratively across the systems of care with partner organizations before an emergency occurs

Example Partners Supporting CYSHCN and their Families/Caregivers



- Among Providers

- Improve coordination with other providers in an emergency by setting up systems and agreements (such as Memoranda of Understanding) for sharing information and resources that support the care of CYSHCN and their families/caregivers
 - Build partnerships with behavioral health organizations as an increased need for behavioral health services will occur
 - Alleviate burden on home-visiting providers whose ability to provide medical care may be interrupted by helping families/caregivers identify additional resource/partners that may be able to provide support and provide anticipatory guidance
- Community-Based and Consumer Directed Organizations
 - Partner with community-based organizations (CBOs) to better understand challenges faced by CYSHCN and families/caregivers in their community
- Schools
 - Partner with schools to minimize disruptions in schooling and use the protective services that schools provide, such as care and supervision for CYSHCN, as well as utilize school resources, such as food programs and school-based health care and mental health care
- State and Federal
 - Build relationships with state, local, tribal, and territorial (SLTT) emergency management and public health agencies that maintain state- and community-wise emergency plans to understand potential resources, threats, and hazards
 - Utilize federal programs that support SLTT and public and private health care and public health emergency planning, such as the [Title V MCH Services Block Grant Program](#), or [ASPR's Health Care Readiness Programs](#)
 - Advise and advocate for the inclusivity of CYSHCN and their families/caregivers in government emergency and response plans to better how SLTT will respond during an emergency
- Emergency Sheltering
 - Support coordination with shelter planners by assisting non-profit organizations with emergency shelter planning to ensure shelters adequately serve CYSHCN and their families/caregivers

Communication

- Develop a crisis communication plan by working with CYSHCN and their families/caregivers to ensure they receive timely and accurate information about hazards and safety during an emergency. Consider:
 - Trusted sources of information for reaching the audience
 - Accessible and culturally and linguistically appropriate messaging
 - Content and frequency of communications
 - Method of communications, such as:
 - Town halls and other spaces of community dialogue
 - Social media platforms
 - Websites
 - Other media such as TV, news outlets, and radio stations
 - Email or texting
 - Print materials and home mailers
 - Public alert and warning systems

Data, Information and Technology

- Promote health equity by leveraging data to better understand the community and effectively tailor emergency plans to lead to better health outcomes after an emergency
- Consider options and processes for patient health data tracking and sharing such as interoperability of medical records, sharing of medical record information, and preventing data loss (especially with out-of-network providers) to be provided with information about health care needs
- Be familiar with state and local registries for identifying and tracking CYSHCN with complex medical cases during an emergency
- Establish and enhance telehealth capabilities to support CYSHCN and their families/caregivers to continue to receive care when in-care person is not feasible

Continuity of Operations Planning and Emergency Preparedness Exercises

- Understand the threats and hazards that are more likely to occur, and what can be done to reduce personal risks and impacts
- Minimize disruptions of care by having a Continuity of Operations Planning (COOP) plan that allows organization to sustain their core essential functions and resume normal operations in a timely manner
- Advocate for the inclusion of CYSHCN and their families/caregivers in exercises and plans as part of whole community planning
- Providers may consider becoming involved in local Health Care Coalitions (HCCs)

Preparedness Considerations for Providers of CYSHCN and their Families/Caregivers

Emergency Scenario	Preparedness Considerations for Providers of CYSHCN and their Families/Caregivers
Infectious Disease Outbreaks	<ul style="list-style-type: none"> • Establish a communications plan for disseminating public health information on impacts to CYSHCN through trusted, diverse sources. • Identify where to procure personal protective equipment (PPE) to help protect the health of CYSHCN in medical and community settings. • Take into consideration the occupational hazards, and the safety of providers supporting CYSHCN such as care coordinators, specialty care providers, behavioral health professionals, etc.
Localized Emergencies	<ul style="list-style-type: none"> • Identify local services to provide support if the emergency results in loss of power or water. • Assist CYSHCN and their families/caregivers in obtaining insurance coverage or authorization for backup medications, devices, or supplies (e.g., extra dosages of medication, backup batteries, consumable supplies, etc.). • Provide specific information to CYSHCN and their families/caregivers on how to access available transportation services, alternate routes, evacuation routes, and safety plans.
Natural and Human-Caused Disasters Requiring Evacuation	<ul style="list-style-type: none"> • Identify communication modes that function without electricity or internet services (e.g., amateur (HAM) radios). • Identify evacuation assistance programs that can support CYSHCN and their families/caregivers. These programs will likely be administered by the local public health department and require CYSHCN and their families/caregivers to register prior to an emergency.

Emergency Scenario	Preparedness Considerations for Providers of CYSHCN and their Families/Caregivers
	<ul style="list-style-type: none"> • Encourage CYSHCN and their families/caregivers to have an emergency kit to bring with them during evacuation/rescue. • Identify options for connecting CYSHCN and their families/caregivers with any required medications during an emergency, as well as supplies (e.g., crutches, walkers, inhalers, sensory tools or kits, medical alert bracelets, weather-appropriate clothing, over-the-counter medicine), keeping in mind low-cost options. • Advise SLTT emergency planners on the needs of CYSHCN and their families/caregivers during evacuation, including accessible transportation needs, and how to reconnect families/caregivers if they are separated. • Recognize that in some cases, CYSHCN and their families/caregivers may not be able to evacuate due to resource constraints, mobility challenges, and/or other family considerations.
<p>Natural and Human-Caused Disasters Not Requiring Evacuation</p>	<ul style="list-style-type: none"> • Share alternative options for using benefit programs with CYSHCN and their families/caregivers, as power outages may impact the ability to use electronic benefit cards or vouchers from programs such as Temporary Assistance for Needy Families (TANF) and the Supplemental Nutrition Assistance Program (SNAP). • Identify and initiate contracts for accessible transportation services, particularly those with equipment and supplies specific for CYSHCN, that would be available in the event that an individual needs transport to a health care facility. • Encourage CYSHCN and their families/caregivers to have an emergency kit to use while sheltering in place.

Key Strategies: Response

The response phase occurs during and immediately following an emergency and consists of actions taken to save lives, mitigate trauma and prevent further damage. This includes coordination for continuity of care, provision of shelter, and support to meet basic needs and medical requirements. During this phase, providers and their partners will execute emergency plans developed during preparedness, in partnership with CYSHCN and their families/caregivers.

Individuals, Families, Caregivers, and Systems of Care

- Understand that CYSHCN and their families/caregivers are most familiar with their needs and can best communicate relevant resources and support systems
- Consider the following actions during response:
 - Keep CYSHCN with their families/caregivers during an emergency to maintain emotional and physical health.
 - Child separation can occur during transport to different medical facilities or because of an emergency occurring while CYSHCN are in school
 - Promote health equity and understand the needs of CYSHCN and their families/caregivers, and connect them with available resources
 - Ensure that assisted and accessible transportation is readily available

- Minimize changes in relocation as frequent movement may cause confusion and anxiety, lead to disjointed systems of care, and negatively impact CYSHCN’s physical and behavioral health
- Behavioral Health Services During Response:
 - Support CYSHCN and their families/caregivers in identifying and treating behavioral health challenges related to, or exacerbated by, the emergency
 - Use a trauma-informed approach to provide age and developmentally appropriate health care and behavioral health services during and after an emergency. Such an approach involves:
 - Ongoing screening for symptoms of trauma
 - Avoiding re-traumatization when counseling or providing behavioral health care
 - Understanding CYSHCN and their family/caregiver structure, cultural context, socioeconomic background and other SDOH
 - Implement previously developed plans for triaging behavioral health needs of CYSHCN such as Psychological First Aid, which includes:
 - Contact and engagement
 - Safety and comfort
 - Stabilization
 - Information gathering on current needs and concerns
 - Practical assistance
 - Connection with social supports
 - Information on coping
 - Linkage with collaborative services

*Common Symptoms of Adjustment Reactions in Children after a Disaster*³

Symptom	Description
Sleep Problems	Difficulty falling or staying asleep, frequent night awakenings or difficulty awakening in the morning, nightmares, or other sleep disruptions.
Eating Problems	Loss of appetite or increased eating.
Sadness or Depression	May result in a reluctance to engage in previously enjoyed activities or a withdrawal from peers and adults.
Anxiety, Worries, or Fears	Children may be concerned about a repetition of the traumatic event (e.g., become afraid during storms after surviving a tornado) or show an increase in unrelated fears (e.g., become more fearful of the dark even if the disaster occurred during daylight). This may present as separation anxiety or school avoidance.
Difficulties in Concentration	The ability to learn and retain new information or to otherwise progress academically.
Substance Abuse	The new onset or exacerbation of alcohol, tobacco, or other substance use may be seen in children, adolescents, and adults after a disaster.
Risk-Taking Behavior	Increased sexual behavior or other reactive risk-taking can occur, especially among older children and adolescents.
Somatization	Children with adjustment difficulties may present instead with physical symptoms suggesting a physical condition.
Developmental or Social Regression	Children (and adults) may become less patient or tolerant of change, revert to bedwetting, or become irritable and disruptive.

³ American Academy of Pediatrics. [Providing Psychosocial Support to Children and Families in the Aftermath of Disasters and Crises](#).

Partnerships and Coordination

- Among Providers
 - Providers can work across the system of care using established partnerships and agreements to identify available services and resources, such as assisted and accessible transportation to health care, medical equipment, service animals, and support for other AFN.
 - Providers may develop agreements with hospitals in the event that a CYSHCN needs to seek a higher level of care during an emergency.
 - Coordinate with prehospital or local emergency medical services (EMS), who are often on the front lines, to support CYSHCN and their families/caregivers as needed
- Community-Based and Consumer Directed Organizations
 - Share contact information with CBOs and other service organizations who are able to provide resources and services during an emergency and advocate for the needs of CYSHCN and about the possible challenges associated with CYSHCN
 - Coordinate across response partners to arrange for assisted and accessible transportation that supports a variety of mobility needs, medical equipment, service animals, and support for other disability needs, if necessary
- Schools
 - Continue to partner with schools and work to identify ways in which they can provide support, such as by serving as shelters or using school buses for transportation
- State and Federal
 - Look to various SLTT government agencies and CBOs for short-term services for CYSHCN and their families/caregivers during an emergency response, such as:
 - Child respite care (e.g., emergency centers, temporary care facilities)
 - Search and rescue services for missing or displaced persons
 - Temporary housing and food assistance
 - Behavioral health through first responders, emergency medical services (EMS), and trained shelter volunteers to provide coping mechanisms and counseling during the emergency
 - [988 Suicide and Crisis Lifeline](#)
 - Technology needs
 - Poison Help Line (1-800-222-1222)
 - Warming or cooling centers, charging stations that are in public buildings (e.g., libraries, community centers, schools)
 - Distribution of supplies for the community
- Emergency Sheltering
 - To ensure CYSHCN and their families/caregivers are taken care of, providers may coordinate with emergency shelters to:
 - Help CYSHCN and their families/caregivers identify open emergency shelters or other care settings appropriate for CYSHCN
 - Advise on caring for CYSHCN and their families/caregivers and to minimize separation of youth or facilitate reunification
 - Identify assisted and accessible transportation working across the system of care and other partners to ensure that they can safely reach the shelter
 - Ensure shelters are following protocols for keeping families together to minimize separation of youth or to facilitate reunification

- Monitor the status of CYSHCN and their families/caregivers who may need to shelter in place due to the CYSHCN’s level of care, resource constraints, or other barriers and refer to acute care settings (e.g., emergency room) if necessary

Continuity of Operations Planning

- Enact COOP plans to sustain services for CYSHCN and their families/caregivers and recommend alternative referrals or alternate care sites to other providers in case of disruption until they are able to resume normal operations

Communication

- Providers and their partners should use the established crisis communication plans as they play significant roles in real-time communication of emergencies and disruptions to coordinate the distribution of clear, timely, accurate, and effective information to CYSHCN and their families/caregivers
- Use messaging that focuses on safety measures, how to prevent further loss, identifying available resources to support the basic needs of CYSHCN and their families/caregivers, and information on where to seek care in the event of an emergency
- Providers should leverage back-up or alternative methods of communication in instances where power may be out, or internet or cell phone service is not available

Data, Information and Technology

- Providers can use data and information sources to monitor emergencies and assess the impacts on CYSHCN and their families/caregivers and use data sources to identify which communities may be disproportionately impacted and require more urgent support as this can help determine which areas need assistance receiving services and select areas for increased needs
- Providers may benefit from using a system to access patients’ medical histories to identify children and families with complex medical needs and find support for them
- Report data related to medical surge and facility capacity to SLTT governments and emergency planners to help identify which facilities have bed availability and an adequate workforce as this information is pertinent for CYSHCN as they are at higher risk of experiencing adverse effects during an emergency

Example Response Considerations for Providers of CYSHCN and their Families/Caregivers

Emergency Scenario	Example Response Considerations for Providers of CYSHCN and their Families/Caregivers
Infectious Disease Outbreaks	<ul style="list-style-type: none"> • Communicate risks of current infectious disease outbreak(s) in plain language, using multiple formats, and in multiple languages to CYSHCN and their families/caregivers. • Work with federal and SLTT public health to specify best approach for MCM dispensing, PPE distribution, and communicating to CYSHCN and their families/caregivers. • Support families in balancing in-person care at medical facilities with telehealth or remote care. This includes physical therapy, occupational therapy, speech therapy, etc. • Distribute equipment to support telehealth care, such as remote patient monitoring devices, and communicate appropriate safety measures for in-person care. • Share information on any impacts of the infectious disease on service animals with CYSHCN and their families and caregivers.

Emergency Scenario	Example Response Considerations for Providers of CYSHCN and their Families/Caregivers
Localized Emergencies	<ul style="list-style-type: none"> • Conduct outreach, in coordination with partners (including CBOs and Family Organizations), to CYSHCN and their families/caregivers to support their health and safety. • Work with partners to meet basic needs, such as clean water to CYSHCN and their families/caregivers, in the event of a water service disruption. • Coordinate with partners to ensure that there is adequate supervision and care for CYSHCN who are temporarily separated from their families/caregivers due to the localized emergency and ensure reunification when possible. • Share information with partner organizations about new community-based needs that have emerged for CYSHCN and their families/caregivers during the emergency.
Natural and Human-Caused Disasters Not Requiring Evacuation	<ul style="list-style-type: none"> • Collaborate with trusted sources of information to share updates on emergency response efforts and the roles that CYSHCN their families/caregivers can play in supporting the response. • Maintain contact with SLTT government agencies and CBOs supporting CYSHCN and their families/caregivers to ensure that those impacted receive necessary supplies and resources. • Support CYSHCN and their families/caregivers in ensuring service and support animals have their basic needs met throughout the emergency. • Collaborate with providers and shelters to provide referrals to address new needs, such as behavioral health and mental health services, power requirements for DME, and refrigeration for medication. • Share information with CYSHCN and their families/caregivers on alternate transportation options that are available for use during the emergency, such as transportation to medical appointments. • Coordinate with shelter providers and staff to provide support for CYSHCN in group homes (e.g., residential childcare communities, treatment centers) and ensure safe accommodations for displaced, unsupervised, or unaccompanied children if the shelter must be evacuated. • Activate agreements with transportation providers to ensure assisted and accessible transportation is available for CYSHCN and their families/caregivers who need to evacuate. • Support CYSHCN disconnected from systems of care (e.g., those who are in foster care, experiencing homelessness, LGBTQIA+, etc.) before, during, and after evacuation as this population may require additional services and support.
Natural and Human-Caused Disasters Requiring Evacuation	<ul style="list-style-type: none"> • Provide real-time alerts to CYSHCN and their families/caregivers through multiple formats and in multiple languages, including sign language. • Implement agreements defined in the preparedness phase to fill roles and responsibilities among organizations caring for CYSHCN, such as provision of communication aids or access to a power source.

Key Strategies: Recovery

The recovery phase of the emergency management cycle occurs after an emergency and requires balancing immediate needs with the goal of establishing a new normal. This process includes repairing infrastructure, restoring services, and identifying long-term mitigation and community resilience

strategies, including addressing the changing climate. Recovery may take longer after emergencies that resulted in damage to infrastructure (e.g., inpatient and outpatient medical facilities, records storage facilities) and utility failures (e.g., power, water). Recovery for CYSHCN and their families/caregivers may continue long after a community has completed physical recovery efforts (e.g., infrastructure repair, clearing debris). It is crucial that CYSHCN and their families/caregivers regain access to health care services, including behavioral health services, as soon as possible during the recovery phase.

Individuals, Families, Caregivers, and Systems of Care

- Work with CYSHCN and their families/caregivers to identify support needed for recovery as it affects their immediate health needs, including social determinants of health. These supports may include:
 - Financial loss or additional financial burdens
 - Loss of health insurance due to relocation
 - Loss or instability of housing due to infrastructure damage, changes in housing affordability, etc.
 - Behavioral health impacts, which may present as sleeping and eating disturbances, problems concentrating on schoolwork, irritability and anger, or somatic symptoms
- Discuss with CYSHCN and their families/caregivers the support they need to recover and resume typical activities, such as:
 - Re-establishing and reconnecting to their systems of care
 - Navigating new and/or worsened health care challenges, changes in access to care, and/or changes to insurance coverage
 - Available government assistance programs
 - Resuming regularly scheduled services, such as medical care, medicine intake, and interactions with specialists
 - Understanding behavioral health challenges and getting referrals for behavioral health services and other therapies, pathology services, etc.
 - Identifying recreational opportunities to reconnect with friends and peers
 - Transitioning back from temporary care settings
 - Accessing long-term recovery and support groups
- Take time to identify and support equitable recovery measures in communities disproportionately impacted by the emergency, especially those who were already medically and economically underserved prior to the emergency
- Providers can refer clients to appropriate systems of care and support CYSHCN and their families/caregivers in:
 - Navigating health insurance policies, such as by sharing information and points of contact and helping to identify which changes to insurance policies may impact them directly.
 - Providers should familiarize themselves with possible changes and amendments to insurance policies, recognizing that policies vary from state to state; providers can contact their state Medicaid agency for specific information. Providers can refer to the Centers for Medicaid and Medicare Service's (CMS) Preparedness and Response Toolkit for [State Medicaid and CHIP Agencies in the Event of a Public Health Emergency or Disaster](#) for more information.
- Providers must work with CYSHCN and their families/caregivers to ensure they are appropriately discharged from temporary or acute care settings, when applicable.

- Priorities must utilize the CMIST framework for patient- and family-centered care, which includes identifying needs for communications, maintaining health, independence, physical and psychological support and safety, as well as transportation needs.
- Providers ought to use a trauma-informed approach to recovery and address behavioral health needs for CYSHCN.
 - This likely will involve collaboration with community partners and working to reconnect CYSHCN and their families/caregivers with their systems of care.

Partnerships and Coordination

- Among providers:
 - Identify alternate access to health care services
 - Update medical records with information that may have changed during an emergency
 - Transition data from acute care providers into medical records
 - Identify resource needs and behavioral health needs, in collaboration with home health providers and/or programs, when appropriate
 - Amplify messages to promote health and development, recovery activities, and additional support systems
- Community-Based and Consumer Directed Organizations
 - Continue to collaborate with CBOs to provide long-term recovery resources to CYSHCN and their families/caregivers, as well as support the formation of Long-Term Recovery Groups (LTRGs) which provide support for and connect survivors to resources
- Schools, SLTT, and Emergency Sheltering
 - Collaborate with school administrations, educators, SLTT government agencies, CBOs, family-led and youth-focused organizations, and other community partners to identify the challenges associated with resuming services and develop plans for service resumption

Continuity of Operations

- Conduct an after-action review to identify areas for improvement and incorporate lessons learned into COOP plans
- Consider impacts to the provider workforce from burnout and attrition caused by changes in providers workflows, which may exacerbate worker shortages or otherwise decrease the availability of providers

Communication

- Focus on communication messages geared towards addressing community resilience and well-being during the recovery phase, while continuing to ensure that messages are easy to understand and culturally sensitive.
- Share relevant and timely information on:
 - The resumption of health care services that may have been paused
 - The availability of hospital beds and staff
 - The status of medication and supply shortages
 - Information from emergency shelters on helping individuals transition to alternate settings
 - How to establish referrals and resources to address emergent needs
 - Available services, such as, health care, behavioral health, and/or social services and how to access those services

Data, Information, and Technology

- Use data to:
 - Promote equity and informed decision-making in the distribution of resources
 - Resume routine care, with data helping to identify gaps, changes, and challenges around the restoration of normal systems of care
 - Evaluate and continue the distribution of equitable resources
 - Monitor health care capacity
 - Identify behavioral health needs and continue to provide services
 - Measure community resilience

Mitigation and Community Resilience

- Providers should approach mitigation and resilience activities from a posture of learning, elevate CYSHCN and their families/caregivers in the decision-making process, such as:
 - Increasing awareness of hazards of risks to communities
 - Strengthening services and supports for SDOH
 - Increasing access and use of data
 - Evaluating the effectiveness of policy changes
 - Advocating for new or additional funding for local services
 - Continuing to build and foster trust with CYSHCN and their families/caregivers
- Providers can address the impacts of climate change in their mitigation and resilience work, due to profound impacts on CYSHCN and their families in the form of:
 - Heat-related illness and death, asthma attacks, foodborne and waterborne illness, and trauma and behavioral health impacts
 - Community climate resilience and mitigation can focus on the impacts of more-frequent natural disasters as they impact CYSHCN, such as:
 - Damaged or closed facilities, and other disruptions to systems of care
 - Damage to infrastructure
 - Disruption to transportation
 - Negative impact on critical infrastructure and traditional livelihoods for indigenous communities
- Providers should consider the following actions to promote climate mitigation and resilience:
 - Identify opportunities for CYSHCN and their families/caregivers to get involved
 - Identify potential hazards and health outcomes
 - Identify and address limitations of public policy, community infrastructure challenges, and assess vulnerabilities
 - Utilize the Building Resilience Against Climate Effects (BRACE) Framework to anticipate climate impacts and assess vulnerabilities; project the disease burden; assess public health interventions; develop and implement a climate and health adaption plan; and evaluate impact and improve quality of activities

Example Recovery Considerations for Providers of CYSHCN and their Families/Caregivers

Emergency Scenario	Example Recovery Considerations for Providers of CYSHCN and their Families/Caregivers
Infectious Disease Outbreaks	<ul style="list-style-type: none"> • Communicate guidance to CYSHCN and their families/caregivers about the lasting effects of an outbreak or infection (e.g., prevention measures, such as annual flu or COVID-19 vaccines and boosters) and about known long-term effects of the infectious disease specific to CYSHCN development. Communication about individual

Emergency Scenario	Example Recovery Considerations for Providers of CYSHCN and their Families/Caregivers
	<p>circumstances and risks should occur one-on-one between providers and CYSHCN and their families/caregivers.</p> <ul style="list-style-type: none"> • Emphasize coping strategies (e.g., reconnecting with friends and family, seeking substance use treatment), particularly for CYSHCN who experienced prolonged periods of social distancing and isolation.
Localized Emergencies	<ul style="list-style-type: none"> • Reach out to CYSHCN and their families/caregivers who missed appointments during the emergency and respond appropriately to any new needs. • Facilitate medical records transfer between providers that provided care for CYSHCN during the emergency. • Provide guidance to CYSHCN and their families/caregivers on repairing or replacing equipment that may have been damaged by a power surge or contaminated water. • Connect CYSHCN and their families/caregivers with assisted and accessible transportation services that enable access to places for outdoor recreation following an emergency.
Natural and Human-Caused Disasters Requiring Evacuation	<ul style="list-style-type: none"> • Communicate public health guidance on long-term impacts of a natural disaster, such as poor air quality and contaminated water sources, and discuss with CYSHCN and their families/caregivers the criteria for safe return to home. • Support continuity of services for CYSHCN and their families/caregivers who are temporarily or permanently relocating out of state. Portability of personal medical records is important to ensure continuity of services. • Revisit care plans for CYSHCN who were hospitalized during the emergency and ensure discharge plans align with the CYSHCN and family/caregiver’s updated support needs. • Identify options for safe assisted and accessible transportation from shelter or other care site back to home, including car seats, wheelchair docking restraints, etc. • Support CYSHCN and their families/caregivers in ensuring portability of medical records and insurance coverage to ensure continuity of services. • Support CYSHCN and their families/caregivers in contacting their state Medicaid agency to help them determine whether their insurance plan allows for replacement or requires new prescriptions for replacement DME and/or back up equipment. • Communicate public health guidance on long-term impacts of a natural disaster, such as poor air quality and contaminated water sources.
Natural and Human-Caused Disasters Not Requiring Evacuation	<ul style="list-style-type: none"> • Revisit care plans and engage CYSHCN and their families/caregivers in shared decision-making if new services are required. • Support distribution of supplies if electricity or water services remain out for an extended period. Connect CYSHCN and their families/caregivers to needed medical supplies, appropriate medications, or other therapeutics. • Disseminate resources to CYSHCN and their families/caregivers on self-guided forms of coping, such as creative self-expression, art, music, theater and more. • Re-establish behavioral health support if it was interrupted during the emergency, or if new needs arise.

Key Tools and Resources

The following includes resource and other relevant tools to help support implementation of the key strategies. HHS is not responsible for the availability or content of the resources provided, nor does HHS endorse, warrant, or guarantee the resources listed below.

Preparedness

At-Risk Individuals & People with Access and Functional Needs

- [Access and Functional Needs \(AFN\) Web-Based Training \(HHS/ASPR\)](#)
- [Children and Youth with Special Healthcare Needs in Emergencies \(CDC\)](#)
- [Be Ready: Tips for Families/Caregivers of Children and Youth with Disabilities & Medical Needs \(EMSC\)](#)
- [Disaster Preparedness Checklist for Families/caregivers with Children with Physical Disabilities \(St. Christopher's Hospital for Children\)](#)
- [Disaster Preparedness Checklist for Families/caregivers with Children with Hearing or Vision Loss \(St. Christopher's Hospital for Children\)](#)
- [Disaster Preparedness Checklist for Families/caregivers with Children with Intellectual or Developmental Disabilities \(St. Christopher's Hospital for Children\)](#)
- [Emergencies and Disasters: Keeping Children and Youth with Special Health Care Needs Safe \(Family Voices\)](#)
- [Emergency Kit Checklist for Families/caregivers with CYSHCN \(CDC\)](#)
- [Guide on Keeping Children with Disabilities Safe in Emergencies \(CDC\)](#)
- [Preparing for Disaster for People with Disabilities and other Special Needs \(FEMA\)](#)
- [Public Health Workbook to Define, Locate, and Reach Special, Vulnerable, and At-Risk Populations in an Emergency \(CDC\)](#)
- [Supporting Children with Special Health Care Needs Planning Resource \(ASPR TRACIE\)](#)

Community Organization Preparedness & Engagement

- [Access and Functional Needs Toolkit: Integrating a Community Partner Network to Inform Risk Communication Strategies \(CDC\)](#)
- [Continuity Plan Template and Instructions for Non-Federal Entities and Community-Based Organizations \(FEMA\)](#)
- [Community Preparedness Toolkit \(FEMA\)](#)
- [Creating Effective Hospital-Community Partnerships to Build a Culture of Health \(AHA, HRET, RWJF\)](#)
- [Engaging Faith-based and Community Organizations: Planning Considerations for Emergency Managers \(FEMA\)](#)
- [FEMA Community Lifelines \(FEMA\)](#)
- [Local FEMA Emergency Office Locator \(FEMA\)](#)
- [World Health Organization Simulation Scenarios \(WHO\)](#)

Family & Children Disaster Preparedness

- [Ready.Kids \(FEMA\)](#)
- [Emergency Kit Checklist for Kids and Families \(CDC\)](#)
- [Emergency Planning with Children \(FEMA\)](#)
- [Family and Caregiver Preparedness \(EMSC\)](#)
- [Family Readiness Kit \(AAP\)](#)

- [F2Fs in an Emergency Environment: On the Ground Response to Sustainable Preparedness \(Family Voices\)](#)
- [Guide for Family Emergency Communication Plans \(FEMA\)](#)
- [List of Federally Produced Guides, Forms, and Websites \(Family Voices\)](#)
- [Maternal-Child Emergency Planning Toolkit \(ASPR\)](#)
- [Preparing for Emergencies: Tips for Families \(Family Voices\)](#)
- [Ready.gov Planning Guidelines \(DHS\)](#)

Health Literacy, Health Equity & Nutrition Security

- [AHRQ Health Literacy Universal Precautions Toolkit \(AHRQ\)](#)
- [Compendium of Federal Datasets Addressing Health Disparities \(OMH\)](#)
- [Cultural and Linguistic Competency for Disaster Preparedness Planning and Crisis Response \(ASPR\)](#)
- [Ensuring Culturally and Linguistically Appropriate Crisis Communication \(ASPR\)](#)
- [Health Equity Guiding Principles for Inclusive Communication \(CDC\)](#)
- [Guidelines for Health Supervision of Infants, Children, and Adolescents \(AAP\)](#)
- [National Standards for Culturally and Linguistically Appropriate Services \(CLAS\) in Health and Health Care \(ASPR\)](#)
- [USDA Nutrition Security: Meaningful Support \(USDA\)](#)
- [Resources for Serving Persons with Limited English Proficiency \(ASPR\)](#)

Pediatric Preparedness

- [Emergency Department Readiness Checklist \(EMSC\)](#)
- [Guide on Creating Preparedness Exercises \(AAP\)](#)
- [Partners in Pediatric Readiness, Emergency Preparedness, and Response Education \(PREPaRE\) Training Package \(PEAL Center\)](#)
- [PREPaRE Companion Toolkit \(PEAL Center\)](#)
- [Pediatric Preparedness Resource Kit \(AAP\)](#)
- [Pediatric Simulation Curriculum for Primary Care \(AAP\)](#)
- [Pediatric Surge Annex Tabletop Exercise Template: Situation Manual \(ASPR\)](#)
- [PedsReady: National Pediatric Readiness Project \(NPRP\) Assessment \(EMSC\)](#)
- [Pediatric Issues in Disaster: Webinar \(ASPR TRACIE\)](#)
- [Pediatric Readiness in the Emergency Department \(AAP\)](#)
- [Pediatric Disaster Checklist \(EMSC\)](#)
- [National Pediatric Readiness Project Toolkit \(EMSC\)](#)
- [Planning for Pediatrics in Disasters \(JEMS\)](#)
- [Supporting Children with Disabilities: Lessons from the Pandemic, A Workshop, Chapter 7 \(National Academies\)](#)
- [Herramientas en Prepararse para una Emergencia Quick Tip Videos \(Spanish\) \(HUNE\)](#)

School-Based Preparedness

- [How Schools Can Prepare for Disasters \(ARC\)](#)
- [National Survey of SBHCs: The Impact of the COVID-19 Pandemic \(School-Based Health Alliance\)](#)
- [Readiness and Emergency Management for Schools \(REMS\): Technical Assistance Center \(Department of Education\)](#)
- [School-Based Health Services – HHS Resources \(HHS\)](#)

- [School Safety and Security \(CISA\)](#)
- [Schoolsafety.gov \(DHS, HHS, DoJ and Department of Education\)](#)

Telehealth Services

- [Medicaid and CHIP Telehealth Toolkit \(CMS\)](#)
- [Providing Telehealth and Distant Care Services in Pediatrics \(AAP\)](#)
- [Telehealth in Emergency Preparedness and Response \(Healthcare Ready\)](#)

Response

At-Risk Individuals & People with Access and Functional Needs

- [Communication Access for People with Limited Speech \(AAC-RERC\)](#)
- [Recommended EMS Guidelines for Children and Youth with Special Health Care Needs \(NC EMSC\)](#)

Communication

- [Access and Functional Needs Toolkit for Communication Strategies \(CDC\)](#)
- [A Communications Toolkit for Public Health Emergencies that Impact Children: Resources for Pediatric Practices, Schools, and Childcare Programs \(PA Department of Health\)](#)
- [Communication Assistance Cards \(ACL\)](#)
- [Communication Picture Boards \(AAC-RERC\)](#)
- [Crisis Communication Plan \(FEMA\)](#)
- [Ensuring Language Access and Effective Communication During Response and Recovery \(HHS\)](#)
- [Family Reunification following Disasters: A Planning Tool for Health Care Facilities \(AAP\)](#)
- [Federal Guides for Developing Plain Language Resources \(CDC\)](#)
- [Guides on Person-Centered Planning \(ASPR\)](#)
- [Plain Language \(GSA\)](#)

Emergency Medical Benefits

- [CMS Resources on Emergency Benefits and Waivers \(CMS\)](#)
- [Medicaid Disaster Response Toolkit \(CMS\)](#)

Emergency Shelter Services

- [CMIST Worksheet \(American Red Cross\)](#)
- [Sheltering Handbook Disaster Services \(American Red Cross\)](#)
- ["Show Me" Communications Tool for Emergency Shelters \(MA DPH\)](#)
- [The ADA and Emergency Shelters: Access for All in Emergencies and Disasters \(DOJ\)](#)

Family Separation, Reunification, and Human Trafficking

- [National Center for Missing and Exploited Children \(NCMEC\)](#)
- [Post-Disaster Reunification of Children: A Nationwide Approach \(FEMA\)](#)
- [Family Reunification following Disasters: A Planning Tool for Health Care Facilities \(AAP\)](#)

Post-Disaster Response Services

- [AAP Decontamination Guidance Statement \(AAP\)](#)
- [Natural Disaster Morbidity Surveillance Individual Form \(CDC\)](#)

Youth & Pediatric Health

- [American Heart Association \(AHA\) Pediatric Advanced Life Support \(PALS\) Courses \(AHA\)](#)
- [Protecting Youth Mental Health: The U.S. Surgeon General's Advisory \(U.S. Surgeon General\)](#)
- [Post-Disaster Child Care Needs and Resources \(ACF\)](#)

- [SAMHSA Disaster Technical Assistance Center Supplemental Research Bulletin: Behavioral Health Conditions in Children and Youth Exposed to Natural Disasters \(SAMHSA\)](#)

Recovery

Post-Disaster Response and Recovery Services

- [Child Reunification Guidance \(FEMA\)](#)
- [CMS Resources on Emergency Benefits and Waivers \(CMS\)](#)
- [Disaster Distress Helpline Peer Support Network \(SAMHSA\)](#)
- [FEMA Individual Assistance Policies \(FEMA\)](#)
- [Medicaid Disaster Response Toolkit \(CMS\)](#)
- [Durable Medical Equipment in Disasters \(ASPR TRACIE\)](#)

Trauma-Informed Care and Behavioral Health

- [Helping Your Child Cope with a Disaster \(CDC\)](#)
- [Helping Children Cope and Adjust After a Disaster \(AAP\)](#)
- [Resources for Child Trauma-Informed Care \(SAMHSA\)](#)
- [Resources for Trauma-Informed Care \(NCTSN\)](#)
- [Disaster Technical Assistance Center \(SAMHSA\)](#)

Mitigation and Community Resilience

- [Building Community Resilience for Children and Families \(NCTSN\)](#)
- [Communities Advancing Resilience Toolkit \(CART\) \(Terrorism and Disaster Center\)](#)
- [FEMA Resilience Analysis and Planning Tool \(RAPT\) \(FEMA\)](#)
- [Emergencies and Indoor Air Quality \(EPA\)](#)

Climate Resilience

- [Assessing Health Vulnerability to Climate Change: A Guide for Health Departments \(CDC\)](#)
- [Building Health Care Sector Climate Resilience \(NOAA\)](#)
- [BRACE Framework Overview Video \(CDC\)](#)
- [Climate and Health Intervention Assessment: Evidence on Public Health Interventions to Prevent the Negative Health Effects of Climate Change \(CDC\)](#)
- [Climate and Health Outlook \(OCCHE\)](#)
- [Climate Change and Social Vulnerability in the United States: A Focus on Six Impact Sectors \(EPA\)](#)
- [Climate Change Resilience and Healthcare System Considerations \(ASPR TRACIE\)](#)
- [Fact Sheet: Flood Cleanup - Protecting Indoor Air Quality \(EPA\)](#)
- [HHS 2021 Climate Action Plan \(HHS\)](#)
- [Heat and Health Tracker \(CDC\)](#)
- [Heat.gov \(NOAA\)](#)
- [Projecting Climate-Related Disease Burden: A Guide for Health Departments \(CDC\)](#)
- [The U.S. Climate Resilience Toolkit \(U.S. Global Climate Change Research Program\)](#)