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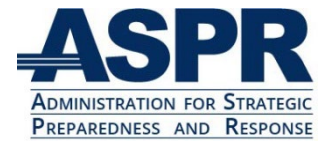
ADMINISTRATION FOR STRATEGIC
PREPAREDNESS AND RESPONSE



HHS Child and Adolescent Health Emergency Planning Toolkit

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

January 2023



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Introduction

Purpose and Audience

The purpose of the *U.S. Department of Health and Human Services (HHS) Child and Adolescent Health Emergency Planning Toolkit: Guidance for Addressing the Needs of Children and Youth with Special Health Care Needs* (this toolkit) is to address the needs of children and youth with special health care needs (CYSHCN) in emergency preparedness, response, recovery, mitigation, and community resilience activities.

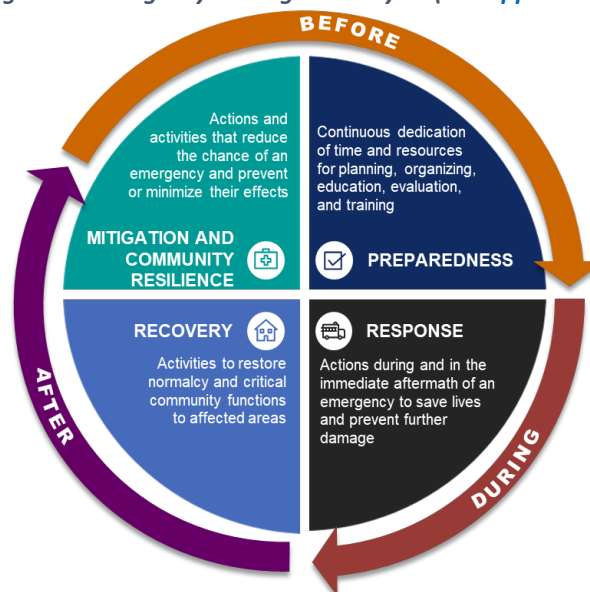
As a companion to the [HHS Maternal-Child Health Emergency Planning Toolkit](#) (Figure 1), this toolkit aligns with ongoing HHS objectives to ensure health equity for all children, adolescents, and CYSHCN and their families/caregivers across the emergency management cycle (Figure 2).

This toolkit also demonstrates alignment with the recommendations set forth by the [National Commission on Children and Disasters \(NCCD\): 2010 Report to the President and Congress](#). This toolkit is intended for health care, public health, and social services providers (providers) serving CYSHCN and their families/caregivers. The toolkit contains approaches, resources, and promising practices to help providers coordinate and integrate systems of care for CYSHCN and their families/caregivers to ensure access to high-quality care, services, and support across the emergency management cycle.¹ By partnering with and supporting CYSHCN and their families/caregivers, providers can reduce the heavy burden of emergency planning that often falls on families/caregivers.

Figure 1: HHS Maternal-Child Health Emergency Planning Toolkit



Figure 2: Emergency Management Cycle (see Appendix A)



¹ Resources that primarily address hospital-based medical care for CYSHCN are provided for reference but are not the focus of this system-based guidance.

Table 1: Audiences for the HHS Child and Adolescent Health Emergency Planning Toolkit

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)² • 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)³ • CYSHCN and their families/caregivers • Emergency management agencies

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.

This toolkit applies an all-hazards approach that focuses on capacities and capabilities that are critical to flexibly planning for a full spectrum of emergencies. This approach ensures that providers have the capacity to address a broad range of emergencies, including localized emergencies (e.g., disruptions in municipal services, such as water, natural gas, electricity, transportation, and schools), natural disasters (e.g. hurricanes, wildfires, floods, tornadoes, earthquakes, extreme weather events), human-caused disasters (e.g., industrial incidents, acts of terrorism, mass violence), and infectious disease outbreaks (e.g., influenza, Zika virus, COVID-19). Providers may consider the likelihood of the different types of events in their community when adopting an all-hazards approach.⁴

Populations Addressed

The previously published [HHS Maternal-Child Health Emergency Planning Toolkit](#) focuses on pregnant, postpartum, and/or lactating people and infants and children (ages 0-5) with typical development. 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.⁵ [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.⁶ This toolkit also addresses the additional emergency planning needs of children with medical complexity, a subset of CYSHCN, as they

² 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.

³ [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.

⁴ Centers for Medicare and Medicaid (CMS). [Survey & Certification Group Frequently Asked Questions \(FAQs\) Emergency Preparedness Regulation.](#)

⁵ Health Resources and Services Administration’s (HRSA). [Children with Special Health Care Needs, National Survey for Children’s Health \(NSCH\) Data Brief.](#)

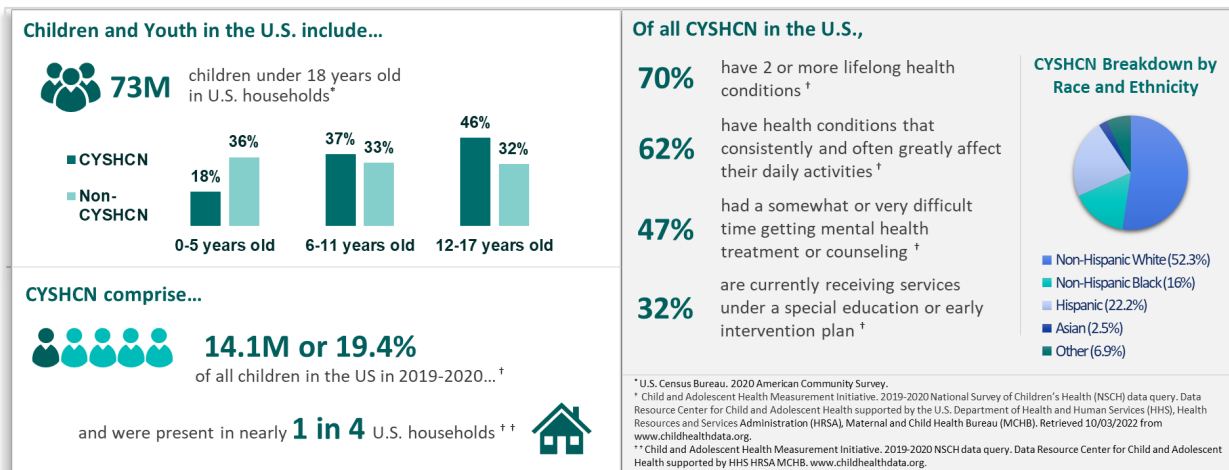
⁶ Sarah E. McLellan, Marie Y. Mann, Joan A. Scott, Treeby W. Brown; *A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families.* *Pediatrics* June 2022; 149 (Supplement 7): e2021056150C. 10.1542/peds.2021-056150C

face additional challenges during emergencies. [Appendix D](#) contains more information on populations and settings.

CYSHCN and their Families/Caregivers

CYSHCN require more and different types of services than those for children and youth with typical development, but the current system does not guarantee access to these services, particularly for CYSHCN impacted by poverty and marginalization.⁷ These services could include but are not limited to home health, behavioral health, and primary care. Emergencies exacerbate these pre-existing challenges and affect the health of children more severely than that of adults. Children’s body size, physical and emotional development, immune system, and decisional capacity elevate their risk of illness or injury, and CYSHCN are more vulnerable to adverse impacts from disruptions in access to electrical power, running water, medications, specialized equipment, and other supplies. As a result, CYSHCN are at increased risk to develop adverse health effects and face higher mortality risks during emergencies.⁸ During emergencies, families/caregivers support CYSHCN by providing physical and emotional safety, support their ability to cope, and assessing and managing any increased physical and behavioral health needs resulting from an emergency.⁹

Figure 3: Key Data on CYSHCN in the U.S.



Children with Medical Complexity

Children with medical complexity, a subset of CYSHCN, are characterized as children having family-identified service needs, severe chronic clinical conditions, functional limitations, and high utilization of health resources.¹⁰ They account for over one-third of pediatric health care costs, mostly arising from inpatient care.¹¹ High quality systems of care for children with medical complexity requires steady continuous communication between the CYSHCN, their families/caregivers, and providers.

⁷ Sarah E. McLellan, Marie Y. Mann, Joan A. Scott, Treeby W. Brown; *A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families*. *Pediatrics* June 2022; 149 (Supplement 7): e2021056150C. 10.1542/peds.2021-056150C.

⁸ Hipper TJ, Davis R, Massey PM, Turchi RM, Lubell KM, Pechta LE, Rose DA, Wolkin A, Briseño L, Franks JL, Chernak E. The Disaster Information Needs of Families/caregivers of Children with Special Healthcare Needs: A Scoping Review. *Health Secur.* 2018 May/Jun;16(3):178-192. doi: 10.1089/hs.2018.0007. Epub 2018 Jun 8. PMID: 29883200.

⁹ Centers for Disease Control and Prevention (CDC). [How are Children Different from Adults?](#)

¹⁰ Eyal Cohen, Dennis Z. Kuo, Rishi Agrawal, Jay G. Berry, Santi K. M. Bhagat, Tamara D. Simon, Rajendu Srivastava; Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics* March 2011; 127 (3): 529–538. 10.1542/peds.2010-0910.

¹¹ Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–538.

Applicability to All Children

While the focus of this toolkit is on CYSHCN, most of the information, resources, and promising practices address the needs of all children and youth generally, many of whom are at increased risk for physical, emotional, and social challenges during emergencies.¹² By improving the capacity and capability of providers to address the needs of CYSHCN in emergency planning, we can safeguard the well-being of all children in emergencies.

Focus on Equitable, Coordinated Emergency Planning

Equitable and coordinated emergency planning can reduce health and social risks, support community strengths, promote community resilience, and support the well-being of CYSHCN. Keeping health equity at the forefront is particularly important for CYSHCN and their families/caregivers living in communities that have limited access to high quality health care, social services, and resources, which increases their risk for being disproportionately impacted by emergencies.¹³

CYSHCN who experience mobility challenges, chronic conditions, and intellectual or developmental disabilities may require multiple levels of coordinated care throughout their lives from diverse “system of care” providers, including providers located within their communities.¹⁴ During emergencies, disruptions to these systems of care may interfere with access to services, potentially compounding existing needs and creating new needs. Ensuring that systems of care work together across all aspects of emergency planning will protect CYSHCN from negative impacts caused by disruptions.

Families and Caregivers as Partners in all Stages of Emergency Planning

CYSHCN and their families/caregivers have better outcomes when a system of services is comprehensive, coordinated, and person- and family-centered, as measured by the indicators in the [“Six Core Outcomes of a Successful System of Care for CYSHCN.”](#) Unfortunately, many CYSHCN still do not receive services in a well-functioning system.¹⁵

Six Core Outcomes of a Successful System of Care for CYSHCN

An optimal system of care for CYSHCN and their families/caregivers is one that promotes coordinated, comprehensive, person- and family-centered systems of services where:

- CYSHCN are screened early and continuously
- CYSHCN receive a [medical home model of care](#) that is person- and family-centered, coordinated, comprehensive, and ongoing
- Community-based services are organized so families/caregivers can use them easily
- CYSHCN receive services necessary to make transitions to adult life, including health care
- Families/caregivers have adequate insurance and funding to pay for services they need
- Families/caregivers of CYSHCN are partners in shared decision-making at all levels of care, from direct care to the organizations that serve them.

In all stages of emergency planning, providers can partner with CYSHCN and their families/caregivers in decision-making so that the needs of CYSHCN are identified and met, especially for those who rely

¹² National Commission on Children and Disasters. [2010 Report to the President and Congress.](#)

¹³ Children’s Bureau, Administration for Children and Families (ACF). [Embedding Equity Into Disaster Preparedness Efforts in Child Welfare.](#)

¹⁴ Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care Coordination for Children with Medical Complexity: Whose Care Is IT Anyway? *Pediatrics*. 2018; 141(3):S225-S232.

¹⁵ Sarah E. McLellan, Marie Y. Mann, Joan A. Scott, Treeby W. Brown; A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families. *Pediatrics* June 2022; 149 (Supplement 7): e2021056150C. 10.1542/peds.2021-056150C.

on subspecialty care, medication, or equipment. Through a person- and family-centered approach, providers demonstrate cultural competency, or respect for an individual and family’s culture, traditions, and communication styles, and actively engage them in planning that takes into consideration their strengths, preferences, and values, in addition to the specific challenges they face. Using a person- and family-centered approach supports self-determination as it relates to health and well-being, relationships, safety, assistance, and more; it empowers the individual to make informed choices as they plan for emergencies. CYSHCN and their families/caregivers should be equal partners in developing services and supports designed for their benefit.¹⁶

Figure 4: Critical Areas for a Well-Functioning System



The HHS Health Resources and Services Administration (HRSA) released a new [framework for a Systems of Services for Children and Youth with Special Health Care Needs \(2022\)](#) as a national agenda to advance the system that serves this population so all CYSHCN can enjoy full lives and thrive in their communities through adulthood. [A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs and their Families/Caregivers](#) highlights how programs and policies at the community, state, and national levels can address inequities that impact health outcomes for CYSHCN. This framework builds on the six core outcomes with a new lens for improving health outcomes by addressing health equity, access to services, financing of services, and quality of life and well-being.¹⁷ This toolkit uses the concepts within the Blueprint to address all four areas, with a focus on health equity across the emergency management cycle.

Toolkit Structure

This toolkit follows the four-phase emergency management cycle employed by the Federal Emergency Management Agency (FEMA) ([Appendix A](#)). Consistent terminology fosters a shared approach to emergency planning and enables better coordination among providers and their partners to address the needs of CYSHCN and their families/caregivers. FEMA’s emergency management cycle incorporates emergency planning that addresses climate change and emerging hazards, which are essential to identify interventions to protect and support CYSHCN and their families/caregivers.¹⁸ The toolkit’s three primary modules are focused on preparedness, response, and recovery, and they include key considerations, recommendations, resources, and real-world examples.

¹⁶ Sarah E. McLellan, Marie Y. Mann, Joan A. Scott, Treeby W. Brown; A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families. *Pediatrics* June 2022; 149 (Supplement 7): e2021056150C. 10.1542/peds.2021-056150C

¹⁷ Ibid.

¹⁸ Federal Emergency Management Agency (FEMA). [U.S. Climate Resilience Toolkit](#).

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 (**Figure 5**).¹⁹

Figure 5: Guiding Concepts and Frameworks



Table 2: Description of Key Frameworks

CMIST Framework	SDOH Framework	Trauma-Informed Approach
<p>This framework provides a flexible, crosscutting approach for planning to address a broad set of common Access and Functional Needs (AFN) without having to define a specific diagnosis, status, or label.²⁰</p> <p>At-risk individuals, including CYSHCN, may have certain needs that must be considered when planning for, responding to, and recovering from an emergency. The CMIST Framework is a recommended approach for integrating the AFN of at-risk individuals.</p> <p>CMIST is an acronym:</p> <ul style="list-style-type: none"> • Communication • Maintaining Health • Independence • Support and Safety (can include Self-determination and Supervision) • Transportation 	<p>SDOH are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. SDOH can be grouped into five domains: economic stability, health care access and quality, social and community context, education access and quality, and neighborhood-built environment.</p> <p>SDOH contribute to wide-ranging health disparities and inequities. Using SDOH, HHS has established goals to “create social, physical, and economic environments that promote attaining the full potential for health and well-being for all.”²¹ (Appendix B)</p> <p>Examples of SDOH include; safe transportation and housing; discrimination; education; access to nutritious foods; and clean air and water.</p>	<p>A trauma-informed approach supports relational health and family resilience as important protective factors for those who have been exposed to persistent adversity or potentially traumatic events. “A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization.”²²</p> <p>Adopting a trauma-informed approach requires constant attention, caring awareness, sensitivity, and possibly a cultural change at an organizational level.^{23,24}</p>

¹⁹ Department of Health and Human Services, Administration for Strategic Preparedness and Response (HHS ASPR). [At-Risk Individuals with Access and Functional Needs: The CMIST Framework](#).

²⁰ HHS ASPR. [At-Risk Individuals](#).

²¹ U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. [Healthy People 2030](#).

²² Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA’s Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.

²³ Centers for Disease Control and Prevention (CDC). [Infographic: 6 Guiding Principles To A Trauma-Informed Approach](#).

²⁴ Administration for Children and Families. [Toolkit for Trauma-Informed Human Services](#).

Relevant Authorities

Section 2814 of the Public Health Service (PHS) Act, as amended, 42 U.S.C. 300hh-16, directs the HHS Secretary to carry out certain emergency preparedness and response activities relating to at-risk individuals, including:

- (1) monitor emerging issues and concerns as they relate to medical and public health preparedness and response for at-risk individuals in the event of a public health emergency declared by the Secretary under section 319;
- (2) oversee the implementation of the preparedness goals described in section 2802(b) with respect to the public health, and medical needs of at-risk individuals in the event of a public health emergency, as described in section 2802(b)(4);
- (3) assist other Federal agencies responsible for planning for, responding to, and recovering from public health emergencies in addressing the needs of at-risk individuals;
- (4) provide guidance to and ensure that recipients of State and local public health grants include preparedness and response strategies and capabilities that take into account the medical and public health needs of at-risk individuals in the event of a public health emergency, as described in section 319C–1(b)(2)(A)(iii);
- (5) ensure that the contents of the strategic national stockpile take into account at-risk populations as described in section 2802(b)(4)(B);
- (6) oversee curriculum development for the public health and medical response training program on medical management of casualties, as it concerns at-risk individuals as described in subparagraphs (A) through (C) of section 319F(a)(2);
- (7) disseminate and, as appropriate, update novel and best practices of outreach to and care of at-risk individuals before, during, and following public health emergencies in as timely a manner as is practicable, including from the time a public health threat is identified;
- (8) ensure that public health and medical information distributed by the Department of Health and Human Services during a public health emergency is delivered in a manner that takes into account the range of communication needs of the intended recipients, including at-risk individuals; and
- (9) facilitate coordination to ensure that, in implementing the situational awareness and biosurveillance network under section 319D, the Secretary considers incorporating data and information from Federal, State, local, Tribal, and territorial public health officials and entities relevant to detecting emerging public health threats that may affect at-risk individuals, such as pregnant and postpartum women and infants, including adverse health outcomes of such populations related to such emerging public health threats.

Section 2802(b)(4)(B) of the PHS Act, 42 U.S.C. 300hh-1, specifies that for the purposes of this Act, the term “at-risk individuals” means children, people who are pregnant, older adults, and other individuals who have access and functional needs in the event of a public health emergency, as determined by the Secretary. For more information on relevant authorities, review [Appendix C: Relevant Legislation and Regulations](#).

Module 1: Preparedness

Overall Considerations

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

Providers can use a person- and family-centered approach and shared decision-making to support CYSHCN and their families/caregivers in preparing for emergencies. Shared decision-making empowers individuals to make their own health care decisions with provider guidance and support. Through the planning process, providers can help CYSHCN and their families/caregivers anticipate certain scenarios and identify resources that are available throughout the emergency management cycle.

“A key part of response and recovery is recognizing that care plans can and do change. Access to needed supports should be clarified ahead of time – recognizing what tends to work for families. Ultimately, in shared decision-making, the family is the expert on the child. The purpose of shared decision-making is not to walk in with a preconceived notion of convincing the other party. It’s also not about deferring to the family. Shared decision-making is a partnership between the care provider and the family. With negotiation, information-sharing, and – most importantly – respect, families are likely to make a good decision on behalf of their children’s needs.” *-Primary Care Physician*

Supporting CYSHCN Disconnected from Systems of Care

In planning preparedness activities, it is important to recognize that some CYSHCN and their families/caregivers have been marginalized and are impacted by intersecting forces of oppression including racism, sexism, classism, ableism, and others. Marginalization and systemic oppression can create distrust towards institutions that have historically or are currently perpetuating inequalities, such as government and health care. For CYSHCN and their families, institutions can begin to restore or build new trust through meaningful engagement with individuals and communities.

CYSHCN may have intersectional characteristics; for example, a high proportion of runaway and CYSHCN experiencing homelessness may also identify as LGBTQIA+. The following are examples of CYSHCN populations who may need a higher level of support and engagement to ensure shared decision-making:

- **CYSHCN in foster care** are at increased risk of injury and illness during emergencies. Their safety and well-being are the legal responsibility of state- child welfare agencies. To better address their needs, providers can aim to exercise shared decision-making and provide comprehensive care through a medical home model. Learn about the [ACF IV-E Foster Care Program](#).
- **CYSHCN experiencing homelessness** are likely have experienced trauma and are more vulnerable to adverse impacts during or after an emergency. To better address their needs, providers can develop resources highlighting how community programs can support school-based success, entry to the workforce, and treatment for substance use disorder.²⁵ Learn about the [ACF Runaway and Homeless Youth Program](#) and [emergency planning for runaway and homeless youth programs](#).

²⁵ Substance Abuse and Mental Health Services Administration (SAMHSA). [Childhood Resilience](#).

- **CYSHCN at risk for human trafficking** due to displacement, separation from families, disconnection from services, and financial burdens. Certain populations are at greater risk, such as youth experiencing homelessness, youth transitioning out of foster care, and individuals with a substance abuse disorder.²⁶ To identify and provide resources for this group, providers can regularly screen and intervene as appropriate. Learn more about [Human Trafficking \(acf.gov\)](#) and [Human Trafficking in the Wake of a Disaster \(cdc.gov\)](#).
- **CYSHCN who are incarcerated** face challenges both during and after their incarceration. Across the U.S., children of color are disproportionately incarcerated for social factors related to poverty and access to adequate care (e.g., living in impoverished communities, undiagnosed or treated behavioral conditions).²⁷ Learn about the [HHS OMH’s Justice and Health Initiatives](#) and [Reentry Resources](#), in addition to [the Juvenile Justice page on youth.gov](#).
- **CYSHCN who identify as lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and more (LGBTQIA+)** may have difficulty finding providers who are knowledgeable about their needs, may experience discrimination from insurers or providers, face barriers to care due to state or local policies, or delay or forego care because of concerns about how they will be treated.²⁸ Additionally, CYSHCN who are receiving gender-affirming care, such as puberty blockers, may experience significant disruptions in their care during an emergency event. Learn about [Making Emergency Plans Inclusive and Emergency Preparedness and Lesbian, Gay, Bisexual and Transgender \(LGBTQIA+\) People](#).
- **CYSHCN and families/caregivers who are immigrants or refugees** may experience barriers to accessing services due to discrimination, lack of access to translation services, or fear of disclosing immigration status.²⁹ Learn about the [U.S. Refugee Resettlement Program](#) and review these resources on [Immigrant Access to Health and Human Services](#) and [Resettlement Services](#).
- **CYSHCN experiencing interpersonal violence, abuse, and/or neglect** can experience worsened abuse in the aftermath of an emergency.³⁰ Providers can work with local and state child welfare and advocacy organizations to disseminate information about services supporting young children, information about child abuse and neglect, and guidelines for reporting suspected child abuse. Providers may also follow local and state guidelines for reporting suspected abuse. Learn about [ACF child abuse and neglect programs](#).

Creating an Individual Emergency Plan

Providers can work with CYSHCN and their families/caregivers to understand the threats and hazards that are more likely to occur in their community and what they can do to minimize personal risks and impacts. (Review [Appendix E](#) for data sources). Providers and CYSHCN and their families/caregivers can work together to create an actionable emergency plan and kit that considers these different types of threats and hazards, in addition to their specific AFN, cultural preferences, and personal and community resources.³¹ Providers may consider talking through a series of sample questions, aligned to the [CMIST Framework](#), to support CYSHCN and their families/caregivers in developing an emergency plan. See [Appendix F](#) for sample questions and providers can also use a sample emergency planning [checklist](#).³²

²⁶ CDC. [Human Trafficking in the Wake of a Disaster](#).

²⁷ HHS Office of Minority Health. [OMH’s Justice and Health Initiatives](#).

²⁸ Seglah, H A & Blanchard, K (2021) [LGBTQIA+ People and Disasters](#).

²⁹ Fussell, E., Delp, L., Riley, K., Chávez, S., & Valenzuela, A., Jr (2018). [Implications of Social and Legal Status on Immigrants’ Health in Disaster Zones](#). American Journal of Public Health, 108(12), 1617–1620. <https://doi.org/10.2105/AJPH.2018.304554>

³⁰ Seddighi, H., Salmani, I., Javadi, M. H., & Seddighi, S. (2021). [Child Abuse in Natural Disasters and Conflicts: A Systematic Review](#). *Trauma, Violence, & Abuse*, 22(1), 176–185. <https://doi.org/10.1177/1524838019835973>

³¹ FEMA. [Developing and Maintaining Emergency Operations Plans](#).

³² FEMA. [Preparing for Disaster for People with Disabilities and other Special Needs](#).

Providers can work with CYSHCN and their families/caregivers to:

- **Individual Care Plans:** Include information and considerations for emergency response in existing individual plans of care, which aim to help minimize disruptions in care during an emergency, such as:
 - Decision-making criteria for when a CYSHCN should seek care in an acute setting during an emergency;
 - Identification of shelters that support their AFN and health needs;
 - Evacuation plans;
 - Transportation considerations and needs;
 - Transition considerations between different levels of care; and
 - An [emergency kit checklist](#).
- **Communications:** Identify primary and alternate methods for communication among CYSHCN, families/caregivers, and providers if cellular service is disrupted (e.g., text messaging, email). Ensure accessible and culturally and linguistically appropriate messaging.
- **Contact Information:** Keep contact information for CYSHCN and their families/caregivers, friends, school, and their system of care providers up-to-date so providers can connect them to CBOs and other services that provide information, resources, and support during and after an emergency.
- **Medical Records:** Work with CYSHCN and their families/caregivers to gather medical records and health information for CYSHCN and ensure they are accurate, up-to-date, and readily accessible in an emergency. Providers can use the [Emergency Information Form \(EIF\)](#) to summarize the CYSHCN's medical history and advise CYSHCN to keep it available, even when neither family/caregivers nor primary care providers are immediately available for CYSHCN who are not capable of self-determination.
- **Device and Technology:** Identify device and technology needs, including backup durable medical equipment (DME) or devices, and any backup power requirements (e.g., batteries, generator).
- **Plain Language:** Determine where and how to find trusted, accurate, and plain language information about the emergency (e.g., websites or social media of local government agencies).
- **Evacuation Plans:** Pre-identify evacuation plans, shelters that can accommodate AFN and health needs, and alternate care settings, should they be required during an event. Consider how the timing of events, such as those occurring during school or work hours, will impact these plans. The large majority of general population shelters can accommodate a broad range of disabilities and conditions. General population shelters are required to meet Americans with Disabilities (ADA) accessibility requirements.³³ Providers can use a trauma-informed approach to help CYSHCN and their families/caregivers identify what they would need when relocating.
 - In some instances, CYSHCN and their families/caregivers may opt to shelter in place due to distance from a shelter; resource constraints; and/or their care needs, particularly for CYSHCN with complex medical needs. Providers can support CYSHCN and their

Story from the Field: Coordinating Care for a Child with Medical Complexity

Providers collaborated with a foster child with medical complexity and their foster care case manager to develop a well-coordinated care plan across their health care and social service providers. The plan ensured a cohesive system of care even when they experienced changes in their foster care placement. The child's case manager played an essential role, providing detailed documentation that helped various specialists track their diagnosis and care plan. When the pandemic began, the child's care team used these documents to address acute issues and modify the child's care plan.

³³ Department of Justice Civil Rights Division. [ADA Checklist for Emergency Shelters](#).

families/caregivers in developing an alternative system of care, which may include telehealth, transportation options, and referrals.

- Some CYSHCN may rely on home nursing services for medical care. During an emergency, access to these vital services may be disrupted and/or unavailable, which poses a significant threat to the health and safety of CYSHCN. When necessary, CYSHCN may use acute care services on a temporary basis to ensure their health and safety. Providers can help CYSHCN and their families/caregivers pre-identify other care settings outside their typical systems of care, such as temporary long-term care facilities, that may be able to provide this higher level of care during an emergency. For more information see [Module 3: Recovery, Access to Care and Health Insurance Coverage](#).
- If a CYSHCN must relocate to a short-term assisted living facility, clearly pre-identify indicator(s) to share at the beginning of their stay that specify when the facility can safely discharge them from the temporary care setting. This planning can help prevent long-term stays and support CYSHCN in more quickly reintegrating into their home communities.
- **Behavioral Health:** Screen CYSHCN for behavioral health needs to identify behavioral health, SDOH, and health equity concerns that may be exacerbated during an emergency. The [American Academy of Pediatrics-Promoting Mental Health](#) recommends screening throughout childhood and with intervention strategies, and the Substance Abuse and Mental Health Services Administration's (SAMHSA) [National Child Traumatic Stress Initiative \(NCTSI\)](#) provides resources for providers, families/caregivers, and others that respond to traumatic childhood experiences to promote a healing and recovery.

Partners in Pediatric Readiness, Emergency Preparedness, and Response Education (PREPaRE) Resources

The PREPaRE resources were developed by cross-sector key partners, including Drexel University; St. Christopher's Hospital for Children; EMSC; the Parent Education and Advocacy Leadership Center; Hispanos Unidos para Niños Excepcionales, Inc.; and Boston University Center for Innovation in Social Work and Health. The [PREPaRE Training](#) (English only), [Herramientas en Prepararse para una Emergencia \(HUNE\)](#) [Quick Tip Videos](#) (Spanish only), and [companion toolkit](#) (English and Spanish) are intended to bring together families and pediatric emergency care coordinators to learn from each, build trust, and practice real-life skills during an emergency, and equip them with practical guidance to improve emergency preparedness and response between families of children with medical complexity and first responders.

Creating an Individual Emergency Kit

Providers, CYSHCN, and their families/caregivers can also work together to prepare an emergency kit, and providers may help to procure certain supplies and medication. Common emergency kit items include, but are not limited, to those in **Figure 6**.³⁴ Additional considerations include:







- Providers may prescribe additional batteries for DME or devices, or prescribe a longer supply of medication (e.g., 90 days vs. 30 days) for inclusion in their emergency kit. Many insurance policies do not permit early prescription refills, which makes it difficult for CYSHCN and their families/caregivers to obtain the necessary supplies for an emergency kit. For more information

³⁴ CDC. [Emergency Kit Checklist for Kids and Families](#).

on insurance waivers and flexibilities, refer to [Module 3. Recovery Access to Care and Health Insurance Coverage](#).

- Some families/caregivers may not be able to purchase and store all items due to income or storage limitations. In these scenarios, providers can collaborate with CBOs that provide emergency kit items, such as the American Red Cross.
- Kits should account for specific needs. For example, the [United Nations Population Fund guidance](#) provides information about creating ‘dignity kits’ which contain both basic supplies (e.g., menstrual products, toothbrushes, etc.) and specialized supplies, such as diapers, formula, or food and supplements to meet specific nutritional needs. Some CYSHCN and their families/caregivers are accustomed to specific foods, have religious beliefs that influence their clothing, or have multigenerational households, so they can personalize their emergency kits to address their needs.

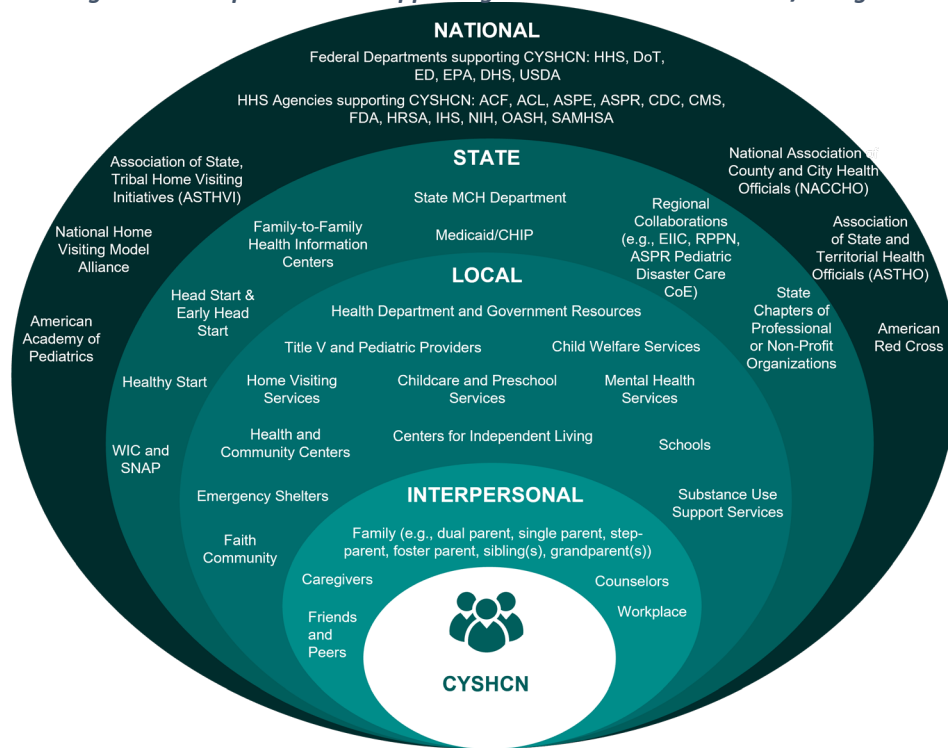
Figure 6: Sample Emergency Kit Items

EMERGENCY KIT					
					
Health Information	Medication, Equipment and Devices	Power and Related Supplies	First Aid Kit	Food and Water	Personal Items
<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 	<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) 	<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 	<ul style="list-style-type: none"> • Antibiotic ointments • Band-aids • Age-appropriate over-the-counter pain relievers 	<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 	<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

Providers can build relationships and work collaboratively across the systems of care and with partner organizations before an emergency occurs. Partners supporting CYSHCN and their families/caregivers include individuals and organizations at the interpersonal, local, state, and national levels (**Figure 7**). Through these collaborations, providers can ensure that partners understand the needs of CYSHCN and their families/caregivers, identify promising practices for coordination, determine roles and responsibilities during response and recovery, and identify available resources.

Figure 7: Example Partners Supporting CYSHCN and their Families/Caregivers



Partnering Among Providers

Many CYSHCN receive care from multiple providers and systems of care. Providers can improve coordination in an emergency by setting up systems and agreements for sharing information and resources that support the care of CYSHCN and their families/caregivers. Providers can improve coordination in an emergency by setting up systems and agreements for sharing information and resources that support the care of CYSHCN and their families/caregivers. Providers may consider partnerships to:

- Identify needs prior to an emergency, such as through programs that provide preventative screening and resources. These programs can also help identify SDOH that may be exacerbated by an emergency.³⁵
- Address increased behavioral health service needs for CYSHCN and their families/caregivers after an emergency. By developing relationships and processes for coordination with a range of behavioral health providers, including those that provide virtual consultation and care, providers can support CYSHCN and their families/caregivers in accessing behavioral health care that is delivered with cultural humility and linguistic competency during and after an emergency.³⁶
- Bridge the health care, public health, and social services needs of CYSHCN and their families/caregivers through home visiting and home health providers. Community health workers, social workers, and nurses who provide these home visiting services form strong relationships with families, providers, and CBOs and are trusted partners in advocating for and

³⁵ Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents. [Promoting Lifelong Health for Families and Communities.](#)

³⁶ Health Resources and Services Administration (HRSA). [Pediatric Mental Care Access.](#)

addressing the needs CYSHCN and their families/caregivers before, during, and after an emergency.

Professional organizations and public agencies have tools that help providers develop collaborative partnerships for emergency planning. For example, the American Academy of Pediatrics (AAP) provides several [online resources and guidance](#) on emergency planning for CYSHCN. Additionally, [HRSA's Emergency Medical Services for Children \(EMSC\) Innovation and Improvement Center \(EIIC\)](#) aims to optimize outcomes for children during emergencies using a multisystem and multidisciplinary approach.

For a representative list of these organizations and establishing working relationships to enable greater information exchange and collaboration in the event of an emergency, see [Appendix G](#). Providers may consider entering into a formal agreement with the organization to define the terms of the partnership and ensure each partner understands their role during an emergency (e.g., [MOUs](#)). For more information on the types of agreements, see [Appendix H](#).

Partnering with Community-Based and Consumer Directed Organizations

CBOs, such as [aging and disability networks](#), [community health centers](#), [childcare providers](#), [service providers for those experiencing homelessness](#), consumer directed agencies, such as independent living centers, family-led organizations, youth-focused activities, recreation centers, community centers, libraries, and faith-based organizations, often have a clear picture of the current programs and services that are used by CYSHCN and their families/caregivers and have a deep understanding of the challenges they face and resources they would likely need during an emergency. CBOs often have established relationships with people who may be marginalized and impacted by intersecting forces of oppression.³⁷ Providers can partner with CBOs to better understand challenges faced by CYSHCN and families/caregivers in their community. CBOs can help coordinate planning activities and serve as a trusted source during an emergency. In addition, providers can help connect CYSHCN to these organizations to become involved in and advocate for their own preparedness needs.

EXAMPLES OF FAMILY-LED AND YOUTH-FOCUSED ORGANIZATIONS

- [The Center for Parent Information and Resources \(CPIR\)](#)
- [Emergency Management Services for Children \(EMSC\), Family Advisory Network](#)
- [Family-to-Family Health Information Centers \(State/Territory F2F\)](#)
- [Family Voices Affiliate Organizations \(FVAO\)](#)
- [FEMA's Teen Community Emergency Response Team \(CERT\) Program](#)
- [FEMA Youth Preparedness Council](#)
- [FEMA Corps](#)
- [HOSA-Future Health Professionals](#)
- [National Federation of Families for Children's Mental Health \(FFCMH\)](#)
- [National Park Services \(NPS\) Youth Conservation Corps](#)
- [Parent to Parent \(P2P\) USA](#)
- [Public Health AmeriCorps](#)
- [Voices of Youth](#)

³⁷ HHS ASPR. [Promising Practices for Reaching At-Risk Individuals for COVID-19 Vaccination and Information](#).

Partnering with Schools

During an emergency, providers can partner with schools to minimize disruptions in schooling and use the protective services that schools provide.³⁸ Schools play an integral role in the daily lives of CYSHCN and can help to support CYSHCN and their families/caregivers in emergencies. For example, schools:

- **Care and Supervision:** Plan to provide care and supervision for CYSHCN until they can be reunited with their families/caregivers if an emergency occurs while CYSHCN are under school supervision.
- **Resource Hubs:** Act as a central location for distribution sites to obtain supplies (e.g., food supplies and other basic needs) and as resource hubs for CBOs in some communities after an emergency, making it easier to connect CYSHCN and their families/caregivers to assistance.
- **School-based care:** Provide school-based health care and mental health services and support CYSHCN with speech, hearing, and visual differences.³⁹
- **Education:** Provide children and youth preparedness education, such as the [Red Cross Pillowcase Project](#), which teaches third to fifth graders about personal and family preparedness.
- **Continuity:** Collaborate to ensure that Individualized Education Program (IEP) and Individual Accommodation Plans (IAP)^{40,41} can be transferred and continued at a new school, in the event of school closure or need for virtual schooling.
- **Sheltering:** Secure one or more large, safe, accessible gathering spaces (e.g., gym, auditorium) that could support emergency shelters and/or serve as points of distributions for water, food, medical supplies (e.g., hand sanitizer and masks), and medical countermeasures (MCMs).⁴² Consideration should be given if schools can accommodate and meet AFN for CYSHCN and their families/caregivers.
- **Power Dependency:** Secure back-up power, which could support individuals with power needs (e.g., mobile phones, electricity-dependent DME and assistive devices).
- **Food Programs:** Host food programs, such as the National School Lunch Program (NSLP) and may be able to provide pre-packaged meals for CYSHCN and their families/caregivers.
- **Social Connectivity:** Facilitate social connections among CYSHCN and their peers, including sports, extracurricular activities, and afterschool programs.

Partnering at the State and National Level

Providers will want to be aware of the state, local, tribal, and territorial (SLTT) emergency management and public health agencies. These agencies maintain state- and community-wide emergency plans and are a valuable partner for understanding resources, threats, and hazards, and how SLTT agencies will respond during an emergency. As part of a [whole community approach](#), which engages the full capacity of public, private, and nonprofit sectors to understand and meet the actual needs of the whole community, providers can advise and advocate for the inclusivity of CYSHCN and their families/caregivers into the government's emergency response and recovery plans, training, and exercises.

³⁸ Society for Research in Child Development. [Understanding the Impacts of Natural Disasters on Children](#).

³⁹ Readiness and Emergency Management for Schools (REMS). [Ensuring Access and Functional Needs are Met Before, During, and After Emergency Incidents](#).

⁴⁰ U.S. Department of Education. [Individuals with Disabilities Education Act](#).

⁴¹ Nemours KidsHealth. [504 Education Plans](#).

⁴² Centers for Disease Control and Prevention. [Health Care Closed Points of Dispensing](#).

There are a range of federal programs that support SLTT and public and private health care and public health emergency planning:

- **[Title V MCH Services Block Grant Program](#)**: State Title V Directors and their CYSHCN program managers can support emergency planning by providing MCH population data resources to support local emergency planning, using Title V flexibilities to address emerging emergency needs.
- **[Maternal, Infant, and Early Childhood Home Visiting \(MIECHV\) Program](#)**: Supports pregnant people and parents with young children who live in communities that face greater risks and barriers to promote optimal health outcomes.
- **[ASPR's Health Care Readiness Programs](#)**: Supports the development of new partnerships and provides leadership, funding, training, resources, and technical assistance that enhance the nation's health care preparedness and response capacity. These programs include the [Hospital Preparedness Program \(HPP\)](#), the [Regional Disaster Health Response System](#), and the [National Special Pathogen System](#).
- **[ASPR's Pediatric Disaster Care Centers of Excellence \(PCOE\)](#)**: As part of the [National Disaster Medical System \(NDMS\)](#), PCOE are cooperative agreements to improve regional disaster response capabilities across the nation for pediatric patients.
- **[CDC Public Health Emergency Preparedness \(PHEP\) Cooperative Agreement](#)**: Provides assistance to public health departments throughout the nation to help health departments build abilities to respond to a range of public health threats. Funded activities focus on the development of emergency-ready public health departments that are flexible and adaptable.
- **[HRSA's Pediatric Pandemic Network \(PPN\)](#)**: Works to empower our nation's children's hospitals and their communities to provide high-quality, equitable pediatric ready emergency care to children every day and in crises.
- **[HRSA's Emergency Medical Services for Children \(EMSC\)](#)**: Funds grants and cooperative agreements to state governments and schools of medicine to provide training related to emergency care for children through research, partnership, and practice.
- **[Individuals with Disabilities Education Act \(IDEA\) Grants](#)**: The Office of Special Education Programs in the Department of Education administers grant programs to states annually to support early-intervention services for infants and toddlers with disabilities and their families, preschool children ages three through five, and special education for children and youth with disabilities.
- **[Pediatric Mental Health Care Access](#)**: Brings behavioral health consultation, training, and support to pediatric primary care and other providers to make identification, diagnosis, treatment, and referrals of behavioral health conditions a priority of children's health care services.
- **[Bright Futures \(AAP\)](#)**: Provides a conceptual framework called Life Course that identifies and explains how the complex interplay of biological, behavioral, psychological, social and environmental factors can shape health across and entire lifetime and for future generations. Includes resources to address long-term risks to health and development.

Providers may refer to the "[Supporting Children with Special Health Care Needs Planning Resource](#)," developed by ASPR and HRSA, highlights existing local, state, and federal programs that could support medical surge for CYSHCN and their families/caregivers in the event of a public health emergency such as the Zika virus.

Providers may also establish agreements with nonprofits or SLTT governments that enable them to request their assistance during a response. Providers may choose to register with their state’s [Emergency System for Advance Registration of Volunteer Health Professionals \(ESAR-VHP\) registry](#) or their local [Medical Reserve Corps](#) chapter to volunteer for deployment, including to deliver health services and essential care to CYSHCN.

Partnering for Emergency Sheltering

Providers can help SLTT governments that collaborate with the American Red Cross and other organizations to operate emergency shelters that address the needs of CYSHCN and their families/caregivers. For more details on operating emergency shelters that serve CYSHCN, and their families/caregivers, review [Appendix I](#). Shelter consideration may include:

- **Communication:** Use communication methods that are guided by the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care (CLAS Standards), including language access and effective communication support (e.g., access to interpretation or translation services). CLAS Standards ensure “effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.”⁴³
- **Maintaining health:** Consider dietary restrictions of CYSHCN (e.g., allergies, specialty formula), hygiene supplies, medical supplies. Establish designated areas for immunocompromised children.
- **Independence:** Provide access to power sources, including purchased or leased backup generators, and accommodations for service animals.
- **Support and safety:** Establish spaces for CYSHCN, such as designated quiet areas, opportunities for recreation, and areas for decreased sensory stimulation, and consider required safety precautions for children with seizure disorders and supplemental oxygen requirements.
- **Transportation:** Provide accessible and safe transportation, including appropriate equipment (e.g., DME, car seat or restraint system) for CYSHCN.

Continuity of Operations Planning

Continuity of Operations Planning (COOP) includes plans and strategies that allow organizations to sustain their core essential functions and to resume normal operations in a timely manner during and after an emergency.⁴⁴ Providers can have a COOP plan in place to sustain services for CYSHCN and their families/caregivers and minimize disruptions to their systems of care. In many cases, SLTT public health agencies will maintain a community COOP plan, which will include relevant information for providers. For more information on COOP planning, see [Appendix J](#). As part of the COOP plan, providers may also consider establishing an Incident Command Structure (ICS) to manage emergencies. See [Appendix K](#) for more information on ICS.

Story from the Field: Florida COOP Requirements

Florida included requirements for developing an emergency plan as part of care coordination for Medicaid managed care contracts for the Children’s Medical Services Health Plan.

⁴³ U.S. Department of Health and Human Services Office of Minority Health (HHS OMH). [National Standards for Culturally and Linguistically Appropriate Services \(CLAS\) in Health and Health Care](#).

⁴⁴ FEMA. [Developing and Maintaining Emergency Operations Plans](#).

Communication

During emergencies, receiving timely and accurate information about hazards and safety is crucial. One of the primary goals of communication before, during, and after an emergency is ensuring that audiences receive clear, timely, and accurate information in plain language. Providers, CYSHCN, and their families/caregivers can work together to establish a [crisis communication](#) plan.⁴⁵ This plan identifies roles, modes, sources, and effective means to communicate information, and can consider the following:

- **Trusted sources of information:** Identify the best messengers for reaching target audiences, such as trusted CBOs, leaders, and individuals (e.g., home visitors, faith leaders, peer influencers), who can amplify messages and reduce fear or distrust. Providers may engage with local public health agencies who have established trusted community leaders through [Community Outreach Information Networks](#) (COINs), which will be particularly important for reaching at-risk populations with access and functional needs.⁴⁶
- **Accessible and Culturally and Linguistically Appropriate Messaging:** Ensure language access and effective communication (e.g., provide access to interpretation and translation services) when engaging CYSHCN and their families/caregivers. For virtual convenings, providers can consider accessible technology options, including Communication Access Real-time Translation (CART) services and an American Sign Language (ASL) interpreter.⁴⁷ Providers can proactively incorporate CLAS standards into messaging by tailoring culturally and linguistically appropriate messaging for diverse populations of CYSHCN and families/caregivers. See [Appendix N](#) for a checklist on ensuring language access and effective communication during response and recovery. CLAS standards for communication include the following actions, which reduce confusion and anxiety and help facilitate timely access to health care and services:
 - Be clear about the steps that CYSHCN and their families/caregivers need to take to prepare for an emergency, using plain language and avoiding jargon.
 - Offer language assistance to individuals who have Limited English Proficiency (LEP) and/or other communication needs.⁴⁸
 - Advise all individuals about the availability of language assistance services in their preferred language through verbal and written communication. Inform individuals that these services will be provided at no-cost.
 - Ensure the competence of individuals providing language assistance and avoid use of untrained individuals and/or minors as interpreters.⁴⁹
 - Provide easy-to-read, large print and multimedia materials and signage in the languages and formats commonly used by the populations in the service area and accessible to individuals with low vision (e.g., braille).⁵⁰
- **Content:** Identify what content to include in communications, the recipient of the information (e.g., child, youth, adult caregiver), and the frequency with which to communicate. Information

Story from the Field: Use of Radio during Hurricane Maria

In the aftermath of Hurricane Maria, [Puerto Rico](#) relied on [local radio stations](#) to provide critical information when television and online communications were not cut off across the island.

⁴⁵Office of Minority Health. [Ensuring Culturally and Linguistically Appropriate Crisis Communication](#).

⁴⁶ CDC Office of Public Health Preparedness and Response. [Public Health Workbook: To Define, Locate, and Reach Special Vulnerable and At-risk Populations in an Emergency](#).

⁴⁷ National Association of the Deaf. [Emergency Preparedness](#).

⁴⁸ Joint Civil Rights Guidance. [Compliance with Title VI of the Civil Rights Act of 1964](#).

⁴⁹ FEMA. [Crisis Communications Plan](#).

⁵⁰ U.S. Department of Health and Human Services Office of Minority Health (HHS OMH). [National Standards for Culturally and Linguistically Appropriate Services \(CLAS\) in Health and Health Care](#).

shared by providers may include reporting service disruptions, sharing details on alternate locations for services, and providing contact information for referrals and/or support services.

- **Method:** Identify methods of communication to use when communicating with CYSHCN and their families/caregivers. Providers can understand the challenges that CYSHCN and their families/caregivers may encounter when accessing digital information and identify partners that may be able to support through technical support (e.g., broadband) and/or education on how to use the technology. Potential communication methods are included in **Table 3**.

Table 3: Methods of Communication

Communication Method	Description
Town Halls and Other Spaces of Community Dialogue	Allow providers to share information and give youth an opportunity to participate in a dialogue around challenges, barriers, needs, and desires. These forums should include translation and interpretation services for ASL and other languages, as needed in the community.
Social Media Platforms	Help providers rapidly share information and collaborate with CBOs, trusted individuals, or community members to amplify key messages. For example, providers may strengthen preparedness messaging for children and youth using social media toolkits, such as the Children and Youth Preparedness Social Media Toolkit. Social media platforms and influencers are key for disseminating information and are often a vehicle for CYSHCN and their families/caregivers to voice their needs and mobilize for social change. Social media also provides opportunities for peer-to-peer communication, enabling CYSHCN to engage with others in their communities on emergency planning topics.
Websites (e.g., Government Websites, Health Clinic Websites)	Enable providers to share information in multiple languages and provide tools that support individuals who speak sign language or are deaf or hard-of-hearing (e.g., videos using ASL or closed captioning). ⁵¹ Websites should meet 508 accessibility requirements .
Other Media, Such as TV, News Outlets, and Radio Stations	Including language-specific TV, enable providers to disseminate information efficiently, and serve as a more accessible communication method for CYSHCN who are visually impaired. Radio, including language specific radio, may enable providers to quickly disseminate information when other modes of communication are unavailable.
Email or Texting	Enables partners to publicize information rapidly, such as through school email accounts or jurisdictional text alert systems. While many individuals have mobile phones, rural communities in particular may experience disruptions to cellular service or broadband during an emergency and low-income families may have limited data plans or availability, making them harder to reach through this method. Providers can identify alternative methods in situations where this may occur.
Print Materials and Home mailers	Including those with braille, in large print, and in multiple languages, help providers easily disseminate more static messages.
Public Alert and Warning Systems	Often administered by SLTT public health or emergency management agencies and provide public safety notices through multiple modes of communication, including email and cellular phones in a danger zone. Many of these alert systems will require pre-registration, so providers can remind CYSHCN and their families/caregivers to register during preparedness planning. Accessibility of these systems is mandated by the Federal Communications Commission.

⁵¹ Department of Homeland Security. [Tips for Effectively Communicating with the Whole Community in Disasters](#); Under Section 1557 of the ACA, covered entities (that operate health program or activity and receive federal financial assistance) are required to post non-discrimination taglines.

Data, Information, and Technology

Emergency planning should be rooted in data and information to ensure plans are relevant to the specific communities, as part of the whole community approach. By identifying and exploring several sources of data, providers can better understand their whole community and more effectively tailor emergency plans, leading to better health outcomes after an emergency.

In addition to the data sources in [Appendix E](#) and the [Census Bureau’s demographic data tools for addressing equity](#), providers may learn that their partners have their own sources of data and/or previously analyzed information on demographics, program and resource utilization, health indicators, and more (*for more information on key partners, review [Module 1: Preparedness, Partnerships and Coordination](#)*). In addition the [Compendium of Federal Datasets Addressing Health Disparities](#) highlights federal programmatic datasets that providers may find useful. Data considerations include:

- Relevant data includes key socioeconomic and demographic characteristics, common threats and hazards, primary populations expected to be affected, potential risks to CYSHCN and their families/caregivers, and current social and health disparities that may be exacerbated by impacts of emergencies, including climate change (*for more information on climate change and climate change resilience, review [Module 3: Recovery, Climate Resilience](#)*).
- When reviewing community-level data, providers may need to adjust their findings to account for the specific impacts on CYSHCN. For example, in planning for chemical exposure, it is important to keep in mind that children are more sensitive to chemical exposures than adults and will have different thresholds with regards to reaching toxic blood levels.

Centering equity requires use of the most timely, accurate, and granular data to account for SDOH, including information on access to care, race/ethnicity data, disability data, cultural practices, spoken language, insurance status, and availability of community resources (e.g., places for recreation). These factors and other aspects of life for CYSHCN and their families/caregivers may influence the challenges they face related to data management and sharing before, during, and after an emergency.

Data Sharing

Providers can consider options and processes for patient health data tracking and sharing, especially with out-of-network providers who may care for CYSHCN during emergencies. This includes interoperability of medical records, sharing of medical record information, and preventing data loss that can be costly both to families and health facilities.⁵² The [Children’s Electronic Health Record \(EHR\) Format](#), which is designed to provide information to EHR system developers to address the health care needs specific to children and youth, especially those enrolled in Medicaid/Children’s Health Insurance Program (CHIP), may be useful for patient data collection and data sharing.⁵³

HHS ASPR Hazard Vulnerability Analysis Template

As part of the Eastern Great Lakes Pediatric Consortium for Disaster Response, HHS ASPR collaborated to build a Hazard Vulnerability Analysis (HVA) Template. The template helps pediatric facilities determine how prepared they are to respond to various hazards, generating scores for risks of hazard impact and vulnerability. This can help providers and pediatricians better understand their own level of preparedness, with actionable steps to improve.

For more information, visit the [HVA Tool Online](#).

⁵² [Forum on Medical and Public Health Preparedness for Catastrophic Events; Board on Health Sciences Policy; Institute of Medicine. Preparedness, Response, and Recovery Considerations for Children and Families: Workshop Summary](#). Washington (DC): National Academies Press (US); 2014 Mar 21. 4, Augmenting State and Local Emergency Plans. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK195869/>.

⁵³ Agency for Healthcare Research and Quality (AHRQ). [Children’s Electronic Health Record Format](#).

Providers may familiarize themselves with state and local registries for identifying and tracking CYSHCN during an emergency, including those with special health care needs and disability status. The Special Needs Tracking and Awareness Response System (STARS) is an example of this system (see text box). At the state level, Oregon developed a [similar system](#), called the Health Emergency Ready Oregon (HERO) Kids Registry, which is a voluntary, no-cost registry that lets families record critical details about their child's health so first responders and hospital emergency departments can quickly and easily access that information in an emergency.

Special Needs Tracking and Awareness Response System (STARS)

[STARS](#) is designed to improve emergency care for children with medical complexities. This program includes the creation of personalized, emergency care plans (including diagnoses, past procedures, medications, allergies, medical equipment, etc.) that are written specifically for EMS and emergency department staff, intensive training, and the development of a centralized web-based system that integrates with 911 dispatching systems. STARS allows medical professionals to access important patient information and care instructions before they arrive at the patient's side.

Additionally, providers can familiarize themselves with child health information privacy laws under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the [Family Educational Rights and Privacy Act \(FERPA\)](#) pertaining to written consent. In emergencies, both HIPAA and FERPA permit the sharing of pertinent information to enable the provision of emergency care without a parent's or adolescent's consent.⁵⁴ An entity covered by HIPAA may share protected health information with disaster relief organizations that are authorized by law or by their charters to assist in disaster relief efforts, for the purpose of coordinating the notification of family members or other persons involved in the individual's care. It is unnecessary in these situations to obtain a patient's permission to share the information in this situation if doing so would interfere with the organization's ability to respond to the emergency.⁵⁵

Telehealth

Telehealth is the "use of electronic information and telecommunications technologies to support health care delivery, health education, public health, and health administration."⁵⁶ Telehealth has been used in various emergencies and helped systems of care become more resilient under stress by connecting patients to providers, educating caregivers on how to provide specific care to CYSHCN, and facilitating consultations between providers and specialists for real-time virtual support, including in rural and under-resourced facilities. In addition to individual preferences and demand, several government initiatives, including grants from the [HRSA Office for the Advancement of Telehealth](#), [Telehealth Resource Centers](#), the [National Emergency Tele-Critical Care Network \(NETCCN\)](#), and the Infrastructure Investment and Jobs Act, are driving the expansion of telehealth across the U.S.^{57,58}

Telehealth can support CYSHCN and their families/caregivers in continuing to receive care when in-person care is not feasible. Providers can establish or enhance telehealth capabilities prior to an emergency so that virtual visits can take place during and after emergencies. Examples of how telehealth may be used before, during, and after an emergency, include:⁵⁹

- Expand access to providers or specialists that would otherwise be inaccessible due to distance (e.g., rural communities), timing (e.g., caregiver works multiple jobs), or other factors.

⁵⁴ HHS. [Health Information Privacy](#).

⁵⁵ HHS. [HIPAA Privacy in Emergency Situations](#).

⁵⁶ Healthcare Ready. [Telehealth in Emergency Preparedness and Response](#).

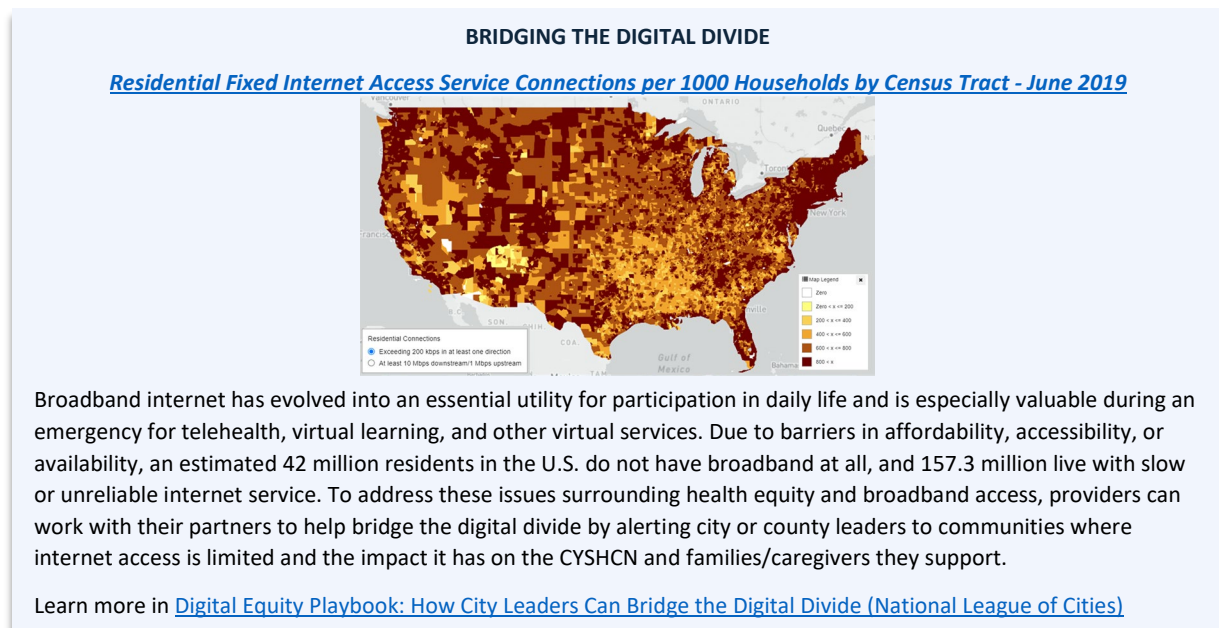
⁵⁷ Text - H.R.3684 - 117th Congress (2021-2022): [Infrastructure Investment and Jobs Act](#).

⁵⁸ Doarn, C. R., & Merrell, R. C. (2014). [Telemedicine and E-Health in Disaster Response](#). *Telemedicine Journal and E-Health : The Official Journal of the American Telemedicine Association*, 20(7), 605–606.

⁵⁹ Healthcare Ready. [Telehealth in Emergency Preparedness and Response](#).

- Maintain recurring appointments with providers, including those addressing trauma-related behavioral health needs, that may otherwise be disrupted by an emergency event.
- Share remote patient monitoring data and transfer health information between providers.
- Access reproductive health services (e.g., contraceptives, sexually transmitted infection (STI) treatment).
- Communicate with providers between in-person appointments (e.g., secure texting).
- Assess home environments, which has shed light into some of the SDOH impacting CYSHCN and their families/caregivers (e.g., food insecurities, safe housing).
- Prevent the need to seek higher levels of care or emergency room utilization for CYSHCN.

In some cases, there may be barriers for CYSHCN and their families/caregivers to access and use telehealth services. Barriers may include limited access to the necessary technology (e.g., smart phones), lack of access to broadband internet, language barriers, or lack of adaptive equipment for people with disabilities.⁶⁰ This may be more prevalent in some communities, such as American Indian and Alaskan Native Communities.⁶¹



Emergency Preparedness Exercises

Preparedness exercises strengthen emergency plans by identifying gaps and areas for improvement and assigning responsibility to mitigate those gaps. As part of whole community planning, the needs of CYSHCN and their families/caregivers should be explicitly included in emergency preparedness exercises at all levels to enable greater continuity of care during and after an emergency. This may include exercising specific scenarios that have greater impact on CYSHCN and their families/caregivers. To ensure CYSHCN and their families/caregivers are considered in emergency planning and to increase the confidence of partners to address these needs, providers can:⁶²

⁶⁰ HRSA. [Health Equity in Telehealth](#).

⁶¹ Bureau of Indian Affairs. [Broadband Access](#).

⁶² Chung S, Gardner AH, Schonfeld DJ, Franks JL, So M, Dziuban EJ, Peacock G. Addressing Children's Needs in Disasters: A Regional Pediatric Tabletop Exercise. *Disaster Med Public Health Prep*. 2018 Oct;12(5):582-586. doi: 10.1017/dmp.2017.137. Epub 2018 Jan 15. PMID: 29332616; PMCID: PMC6046276.

- Plan and conduct discussion-based exercises as part of their organization’s annual preparedness planning. Consider inviting CYSHCN and their families/caregivers to participate in planning and conducting exercises, including discussion-based exercises (e.g., tabletop exercises or drills) and full-scale exercises that are administered by SLTT public health and/or emergency management agencies.⁶³
- Capture lessons learned from exercises to identify areas for improvement and how providers can better support CYSHCN and their families/caregivers during an emergency.
- Get involved with the [local HCC](#) and participate in preparedness exercises with the other coalition members, such as the Pediatric Surge Annex Tabletop Exercise that is required of all HCCs as part of ASPR’s HPP cooperative agreement.

⁶³ Abulebda K, Yuknis ML, Whitfill T, Montgomery EE, Pearson KJ, Rousseau R, Diaz MCG, Brown LL, Wing R, Tay KY, Good GL, Malik RN, Garrow AL, Zaveri PP, Thomas E, Makharashvili A, Burns RA, Lavoie M, Auerbach MA; Improving Pediatric Acute Care Through Simulation (ImPACTS). Preparedness for Pediatric Office Emergencies: A Multicenter, Simulation-Based Study. *Pediatrics*. 2021 Sep;148(3):e2020038463. doi: 10.1542/peds.2020-038463. PMID: 34433688.

Preparedness Considerations for Providers in Various Emergency Scenarios

Providers may consider specific actions that they can take during preparedness to address the needs of CYSHCN and their families/caregivers for a variety of emergency scenarios.

Table 4: Example 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 (e.g., influenza, COVID-19)	<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 (e.g., disruption in municipal services such as water, natural gas, roads, and transportation)	<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 (e.g., hurricanes, wildfires)	<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. 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.
Natural and Human-Caused Disasters Not Requiring Evacuation (e.g., industrial incidents, acts of terrorism, mass violence)	<ul style="list-style-type: none"> Establish telehealth capabilities to enable continuity of care for CYSHCN in the event their care is disrupted. 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.

Preparedness Tools and Resources

The following includes resources mentioned in Module 1, in addition to other relevant tools. HHS is not responsible for the availability or content of the resources provided, nor does HHS endorse, warrant, or guarantee the resources listed below. It is the responsibility of the user to determine the usefulness and applicability of the resources provided.

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 \(OMH\)](#)
- [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 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 \(Healthcare Ready\)](#)

Module 2: Response

Overall Considerations

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 in [Module 1: Preparedness](#) in partnership with CYSHCN and their families/caregivers.

Individuals, Families, Caregivers, and Systems of Care

In emergency response, the most important partners are CYSHCN and their families/caregivers. When making changes to systems of care due to an emergency, providers can practice shared decision-making with CYSHCN and their families/ caregivers. This will help providers better understand, value, and protect the CYSHCN's and their family/caregiver's priorities for their health and well-being.⁶⁴

Providers can consider the following actions during response:

- **Keep Families Together:** Keep CYSHCN with their families/caregivers during an emergency to maintain emotional and physical health. Child separation in an emergency may occur, for example, during transport to different medical facilities; if a CYSHCN or family/caregiver requires services at a health care facility that does not allow family members or visitors; or because a child is at a childcare facility or school and a family member/caregiver is unable to reach them. If separated, “reunifying unaccompanied minors and separated or missing children with their parents or legal guardians in the aftermath of a disaster is a priority” per the [Post-Disaster Reunification of Children: A Nationwide Approach](#). Family separation places additional stress on CYSHCN, particularly if they are in an unfamiliar environment with people they do not know. Family separation also has complex effects on CYSHCN and families/caregivers, surfacing new issues related to trust, attachment, and behavioral health. Providers can use tools, such as the [Hospital Reunification Template](#), to support reunification. In some cases, collaboration with emergency shelter managers may be necessary to ensure they are aware of and following protocols for keeping families together.
- **Promote health equity:** During and immediately after an emergency, CYSHCN and their families/caregivers experiencing socioeconomic and other disparities will likely be disproportionately impacted and require additional resources and support, as seen in COVID-19.⁶⁵ Providers can work with CYSHCN, their families/caregivers, and other partners to better understand the needs and connect them with available resources.

Key Study:
[COVID-19 Cases and Deaths by Race/Ethnicity: Current Data and Changes Over Time](#)

People of color experienced a disproportionate burden of COVID-19 cases and death, including:

- Asian, Native Hawaiian, and Other Pacific Islander (NHOPI), Hispanic, and American Indian/Alaska Native (AI/AN) people are at ~1.5x greater risk of COVID-19 infection than White people.
- NHOPI, Hispanic, AI/AN, and Black people are ~2x as likely to die from COVID-19 as their White counterparts.
- There are large disparities in COVID-19 hospitalizations for AI/AN, Black, and Hispanic people.

⁶⁴ Richard C. Adams, Susan E. Levy, Council on Children with Disabilities, Kenneth W. Norwood, Timothy Brei, Lynn F. Davidson, Beth E. Davis, Kathryn A. Ellerbeck, Amy J. Houtrow, Susan L. Hyman, Dennis Z. Kuo, Garey H. Noritz, Mary O'Connor Leppert, Larry Yin, Nancy A. Murphy, Sandra L. Friedman; Shared Decision-Making and Children With Disabilities: Pathways to Consensus. Pediatrics June 2017; 139 (6): e20170956. 10.1542/peds.2017-0956

⁶⁵ Kaiser Family Foundation. [COVID-19 Cases and Deaths by Race/Ethnicity: Current Data and Changes Over Time](#).

- **Assisted and Accessible Transportation:** Work with CYSHCN and their families/caregivers, as well as shelter managers and other alternate care settings as appropriate, to ensure that assisted and accessible transportation is readily available. If CYSHCN require transfer, such as to a hospital for emergency treatment, providers can coordinate with CYSHCN and their families/caregivers.

Key Study:
[The Effect of Movement and Displacement on Child Health after Hurricane Katrina](#)

A 2006 study on Hurricane Katrina revealed that long-term displacement had major impacts on the behavioral health of children and families. Displaced children were more likely to suffer from or develop special health care needs, including emotional, developmental, and learning disabilities. Approximately half of the children who received care from a medical home before the hurricane lost their system of care permanently in the aftermath. Frequent movement due to relocation disrupted education and caused housing and income instability for children and their families. Effects on parents' or caregivers' behavioral health increased the risk of behavioral health disability and long-term trauma in children.

- **Minimize Changes in Relocation:** Encourage CYSHCN and their families/caregivers to minimize changes in location, as frequent movement may cause confusion and anxiety, lead to disjointed systems of care, and negatively impact the physical and behavioral health of CYSHCN and their families/caregivers. If a CYSHCN is temporarily relocated, it is vital that providers coordinate with them and their families/caregivers to identify the least restrictive setting that takes into consideration the individual's aspirations, needs, preferences, and values. Providers should also take steps that enable CYSHCN to return to their home or original system of care, avoiding unnecessary or inadvertent placement in a longer-term care setting. Providers can document their recommendations within the CYSHCN's individual care plan, as noted in [Module 1: Creating an Individual Emergency Plan](#).

Behavioral Health Services During Response

Traumatic experiences, including those caused or exacerbated by emergencies, can have lifelong impacts on behavioral health and overall development.⁶⁶ Additionally, some CYSHCN may have trouble processing their experiences during and after an emergency. In particular, CYSHCN who were separated from families/caregivers may feel anxious and scared and may later experience posttraumatic stress symptoms (PTSD) and/or depression.⁶⁷ Additionally, some CYSHCN may have trouble processing their experiences during and after an emergency, resulting in symptoms of adjustment reaction, such as those shown in **Table 5**. In particular, some CYSHCN with neurodevelopment issues may lose skills and developmental milestones they acquired prior to the emergency or return to behaviors they have outgrown.^{68,69} It is important to have additional supports during an emergency for some populations of CYSHCN that may have a higher risk for suicide at baseline, such as American Indian and Alaska Native (AI/AN).⁷⁰

⁶⁶ Heather Forkey, et al. The Council on Foster Care, Adoption, and Kinship Care, Council on Community Pediatrics, Council on Child Abuse and Neglect, Committee on Psychosocial Aspects of Child and Family Health, Trauma-Informed Care. *Pediatrics* August 2021; 148 (2): e2021052580. 10.1542/peds.2021-052580

⁶⁷ Osofsky, J.D., Osofsky, H.J. (2013). [Lessons Learned About the Impact of Disasters on Children and Families and Post-disaster Recovery](#). In: Culp, A. (eds) *Child and Family Advocacy. Issues in Clinical Child Psychology*. Springer, New York, NY. https://doi.org/10.1007/978-1-4614-7456-2_7

⁶⁸ *ibid*

⁶⁹ American Academy of Pediatrics. [Providing Psychosocial Support to Children and Families in the Aftermath of Disasters and Crises](#).

⁷⁰ SAMHSA. [Suicide Clusters within American Indian and Alaska Native Communities: A Review of the Literature and Recommendations](#).

Table 5: Common Symptoms of Adjustment Reactions in Children after a Disaster⁷¹

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.

Providers can use a trauma-informed approach to provide age- and developmentally-appropriate health care and behavioral health services to CYSHCN, and their families/caregivers during and after an emergency. A trauma-informed approach involves:⁷²

- Ongoing screening for symptoms of trauma, which can include emotional and communication difficulties, behavioral changes, loss of attention, and anxiety. A follow-up screening can be conducted to identify any significant changes from the previous screenings prior to the emergency as noted in [Module 1: Preparedness, Creating an Individual Emergency Plan](#).
- Avoiding re-traumatization when counseling or providing behavioral health care. Re-traumatization is "a current experience is subconsciously associated with the original trauma, reawakening memories and reactions, which can be distressing. This type of reaction is common and survivors should realize there are steps that can be taken to manage or relieve symptoms."⁷³
- Understanding the CYSHCN’s medical history, as emergencies may disproportionately impact CYSHCN.
- Understanding CYSHCN and their family/caregiver structure, cultural context, socioeconomic background, and other SDOH. Family norms, including cultural and religious norms, can also affect how CYSHCN respond and heal from trauma.⁷⁴

During a response, providers can implement their previously developed plans for triaging behavioral health needs of CYSHCN, such as using [Psychological First Aid](#). If a CYSHCN or their family/caregiver is

⁷¹ American Academy of Pediatrics. [Providing Psychosocial Support to Children and Families in the Aftermath of Disasters and Crises](#).

⁷² NCTSN. [About Child Trauma](#).

⁷³ Child First. [Tips for Survivors of a Disaster or Other Traumatic Event: Coping with Retraumatization](#).

⁷⁴ NCTSN. [Family Centered Treatment](#).

showing signs of behavioral health challenges, including intimate partner violence and substance use, providers can reach out to trained professionals for screening and treatment.

PSYCHOLOGICAL FIRST AID

- 1. Contact and Engagement:** To respond to contacts initiated by survivors, or to initiate contacts in a non-intrusive, compassionate, and helpful manner.
- 2. Safety and Comfort:** To enhance immediate and ongoing safety and provide physical and emotional comfort.
- 3. Stabilization (if needed):** To calm and orient emotionally overwhelmed or disoriented survivors.
- 4. Information Gathering on Current Needs and Concerns:** To identify immediate needs and concerns, gather additional information, and tailor Psychological First Aid interventions.
- 5. Practical Assistance:** To offer practical help to survivors in addressing immediate needs and concerns.
- 6. Connection with Social Supports:** To help establish brief or ongoing contacts with primary support persons and other sources of support, including family members, friends, and community helping resources.
- 7. Information on Coping:** To provide information about stress reactions and coping to reduce distress and promote adaptive functioning.
- 8. Linkage with Collaborative Services:** To link survivors with available services needed at the time or in the future.

To learn more, review [NCTSN's About PFA](#) and [Psychological First Aid for Displaced Children and Families](#).

Behavioral health professionals are part of a multidisciplinary team that can work alongside CYSHCN and their families/caregivers in shared decision-making around behavioral health screening and treatment options. During response, providers can identify possible behavioral health resources, such as a Mobile Crisis Unit, which includes a team of trained specialists, such as psychiatrists, behavioral health providers, nurses, and social workers who provide care during emergencies (e.g., primary care, behavioral health services). These units offer community members an alternative to contacting 911 during emergencies.

[CMS provides guidance and enhanced funding](#) under the American Rescue Plan for states providing community-based mobile crisis intervention services to Medicaid beneficiaries. Mobile crisis intervention services seek to meet people in crisis where they are and rapidly provide critical services to people experiencing mental health or substance use crises by connecting them to a behavioral health specialist 24 hours per day, 365 days a year.

Partnerships and Coordination

During an emergency, CYSHCN and their families/caregivers may reach out to their providers to seek assistance and information. Providers can coordinate with existing systems of care and with partners from [Module 1: Preparedness, Partnerships and Coordination](#).

Partnering 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. In addition, providers may develop agreements with hospitals in the event that a CYSHCN needs to seek a higher level of care during an emergency. Further, because critically ill children cared for in emergency departments that are well prepared to care for children have lower mortality rates, community emergency departments can work to improve their pediatric readiness for everyday emergencies and disasters. The National Pediatric Readiness Project helps all hospitals develop essential guidelines and resources in place to provide effective emergency

care to children.⁷⁵ Providers may consider connecting with a local [Pediatric Pandemic Network](#) to strengthen disaster preparedness for CYSHCN.

Prehospital or local emergency medical services (EMS) are often the front-line providers that assess, provide care, transport, and evacuate CYSHCN and their families/caregivers in response. Working with local and state EMS agencies, EMS providers are integrally involved in setting up emergency shelters including those that address the needs of CYSHCN. They may also take a proactive role in reaching out to CYSHCN and their families/caregivers in their community to help them become aware of the community's emergency plan. In addition, they need to be prepared to address the needs CSHCN and their families/caregivers in an emergency. The services they provide may range from simply helping families use car batteries as a back-up power source if needed, to more complex issues such as providing medical care that is on the CYSHCN's emergency information form or having appropriate equipment to safely transport and care for CYSHCN.⁷⁶

Partnering with Community-Based and Consumer Directed Organizations

Providers can continue to serve as advocates alongside CYSHCN and their families/caregivers and provide peer-to-peer assistance, such as informing CBOs about the emergent needs of, and challenges faced by, CYSHCN and their families/caregivers. Providers may share their contact information with CBOs and other service organizations, such as [Family-to-Family Health Information Centers \(F2F HICs\)](#), who may be able to provide needed resources and services.

Partnering with Schools

During response, schools will continue to be a critically important partner as discussed in [Module 1: Partnering with Schools](#). For example, communities may use schools for shelter or school buses to help evacuate to emergency shelters, hospitals, or deliver supplies. During the COVID-19 pandemic, some school districts converted their buses into Wi-Fi hotspots for students who did not have reliable internet access for virtual learning.

Partnering at the State and National Level

In addition to the programs mentioned in [Module 1: Partnering at the State and National Level](#), federal, SLTT government agencies, and CBOs may offer short-term services to CYSHCN and their families/caregivers during emergency response. These include, but are not limited to:

- **Child respite care:** Organizations may provide families with short-term childcare services in temporary settings (e.g., emergency shelters, temporary care facilities).⁷⁷
- **Search and rescue services for missing or displaced persons:** Organizations, such as the [National Center for Missing and Exploited Children \(NCMEC\)](#) may activate the [National](#)

Story from the Field: Systems of Care through Schools during the COVID-19 Pandemic

During the COVID-19 pandemic, families, schools, providers, and payers collaborated to address disruptions and create new pathways to access school-based services. For example, in some cases physical therapy shifted to a clinical setting, behavioral health services transitioned to telehealth appointments, and behavioral health professionals were invited to classrooms to increase awareness around services and help students identify when they needed help for themselves or family members. Schools served as a venue for virtual or in-person screenings in collaboration with community behavioral health professionals.

⁷⁵ EMSC Innovation and Improvement Center. [National Pediatric Readiness Project](#).

⁷⁶ Kaziny Brent D. [The Prehospital Care of Children With Special Health Care Needs](#), Clinical Pediatric Emergency Medicine, Volume 15, Issue 1, 2014, Pages 89-95, ISSN 1522-8401, <https://doi.org/10.1016/j.cpem.2014.02.001>.

⁷⁷ ACF. [Post-Disaster Child Care Needs and Resources](#).

[Emergency Child Locator Center \(NECLC\)](#) depending on the size and scale of the emergency. The NECLC assists with the reunification of children separated from their parents or legal guardians during a disaster.⁷⁸ The [Unaccompanied Minors Registry](#) also provides a platform to report information about missing children and youth who have been separated from their families as the result of an emergency.

- **Temporary housing and food assistance:** Depending on the size and scope of the event, FEMA and/or other agencies may provide temporary housing assistance, lodging expenses reimbursement, home repair, or home replacement. Providers can connect CYSHCN and their families/caregivers to [the Disaster Assistance Improvement Program](#) to apply for this resource, as applicable.
 - **Disaster Supplemental Nutrition Assistance Program (D-SNAP) Benefits:** The USDA and the Federal Nutrition Service may expand SNAP eligibility during an emergency to cover many affected families. Households can use a simplified and expedited application to apply for and receive up to one month of SNAP benefits within 72 hours of an emergency's onset.
 - **National School Lunch Program:** During an emergency response, the National School Lunch Program may expand eligibility for children to receive free or discounted meals in schools, including automatic expanded eligibility for those who may reside in or have evacuated from disaster areas. Emergency sites may distribute food in the event of school closures. During the COVID-19 pandemic, [the USDA Food and Nutrition Service](#) granted program flexibilities and contingencies across its 15 nutrition programs, such as allowing states to provide electronic benefits to children who normally receive free or reduced-price school meals and serving meals outside traditional times and in non-group settings.
 - **Temporary Assistance for Needy Families (TANF):** Federal government provides states support to establish monthly cash assistance grants to low-income families with children, as well as other services, and may offer flexibility during an emergency. Benefits and requirements vary based on the state, territory or tribal government administering the TANF program.
- **Behavioral health services:** First responders, EMS, and trained shelter volunteers, may provide services to help CYSHCN and their families/caregivers cope during emergencies. [SAMHSA's Disaster Distress Helpline](#) provides 24/7, 365 day-a-year crisis counseling to people experiencing emotional distress related to emergencies and disasters. Disaster Distress Helpline crisis counselors are trained to support disaster survivors and responders throughout the disaster cycle, including during the acute phase and long-term recovery. In addition, providers may utilize [SAMHSA's Disaster Technical Assistance Center](#) for additional resources.
- **988 suicide and crisis lifeline:** The lifeline provides 24/7/365 free and confidential support for people experiencing mental health or substance use crisis. The lifeline can provide support, engage local mobile crisis and/or specialized local behavioral health services, and link to locally available and online supports.
- **Poison:** If there are concerns about a possible poison emergency, that someone may have been poisoned, call the toll-free Poison Help Line (1-800-222-1222) which immediately connects individuals to experts in their local poison control center. These experts can assess and give guidance that may reduce the need to visit the emergency room.

⁷⁸ National Center for Missing and Exploited Children. [Disaster Preparedness and Response \(missingkids.org\)](#)

- **Technology needs:** The [State Grant for Assistive Technology Program](#) supports state efforts to improve the provision of assistive technology to individuals with disabilities of all ages through comprehensive, statewide programs that are consumer-responsive. Contact your [state and territory assistive technology programs](#) for more information on available services.
- **Warming or cooling centers:** Public and private entities (e.g., community centers, schools, libraries) may open their facilities to provide heat, air conditioning, and/or charging stations for the public per previously established agreements.
- **Distribution of supplies to the community:** Federal, SLTT, CBOs, and other partners may establish sites for distribution of supplies. Providers can refer CYSHCN and their families/caregivers to these locations or to help identify alternate methods for receiving supplies, such as home delivery. For example, during the COVID-19 pandemic, local businesses in the U.S. donated goods and services to communities and to the health care and public health workforce.

Coordination with Emergency Shelters

In the early stages of an emergency response, providers, CYSHCN, and their families/caregivers can collaborate with emergency planners, public health agencies, and other organizations to:

- Locate open emergency shelters or other care settings appropriate for CYSHCN and their families/caregivers.
- Identify shelters that have areas for immunocompromised CYSHCN and other medical needs.
- Confirm that assisted and accessible transportation is readily available to evacuate to the shelter or in the event a CYSHCN needs to be transferred from the shelter to an alternate location, such as to a hospital for emergency treatment.
- Advise emergency shelters on the specific needs and preferences of CYSHCN and their families/caregivers.
- Ensure shelters are following protocols for keeping families together to minimize separation of youth or to facilitate reunification. For more information on how shelters can help with reunification of CYSHCN and their families/caregivers, refer to [Appendix L](#).
- 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 departments, hospitals) if necessary. Providers may also work across the system of care to conduct home visits once it is safe.

Continuity of Operations Planning

During an emergency, providers can enact their COOP plans, as discussed in [Module 1: Continuity of Operations Planning](#), to sustain services for CYSHCN and their families/caregivers. If there is a disruption to services, providers can recommend alternative referrals or alternate care sites to other providers until they are able to resume normal operations. When possible, providers can communicate directly with the alternate care site to ensure a smooth temporary transition between systems of care. Additionally, CYSHCN and their families/caregivers can have a hard and/or digital copy of their individual care plan to share with the providers.

Communication

Providers and their partners play significant roles in real-time communication of emergencies. It is important for providers and their partners to use established crisis communication plans, as discussed in

[Module 1: Communication](#), to coordinate the distribution of clear, timely, accessible, and accurate information to CYSHCN and their families/caregivers using CLAS standards and multiple modes of communication. Continuous communication is vital for CYSHCN as it may prevent acute hospitalizations or changes in medical conditions. Providers can use back-up or alternative methods of communication in instances of power outages or if internet or cell phone service is not available. During response, messages should focus on:

- Safety measures and how to prevent further loss (e.g., safety measures to mitigate exposure to a toxic agent, evacuation routes, risks of carbon monoxide poisoning, and other known hazards).
- Available resources to support the basic needs of CYSHCN and their families/caregivers during and immediately after an emergency.
- Information on where to seek care in the event of an emergency, such as open shelters, alternate care sites, and which hospitals are experiencing increased wait times related to surges. Providers can use tools that are specifically designed to communicate with individuals during an emergency, including CYSHCN and families/caregivers who are deaf or hard-of-hearing and those with LEP. These tools include, mobile applications, speech generating devices, and communication boards, such as [Communication Assistance Cards](#), the [“Show Me” Communications Tool for Emergency Shelters](#), and [Communication Picture Boards](#).

During an emergency, providers may receive information from partners directly, through local collaborations, or from federal communications, such as the CDC’s Health Alert Network (HAN). Information shared with providers may include:⁷⁹

- Disruptions to health care services.
- Current or potential medical surge at area hospitals and clinics.
- Delays in accessing or dispensing medicine.
- Shortage of medical supplies and/or equipment.
- Locations providing additional health services (e.g., alternate care sites) or that are equipped with backup generators for CYSHCN and their families/caregivers who depend on power for medical needs and devices.
- Locations of, and directions to, emergency shelters.

CDC Health Alert Network (HAN)

[CDC’s HAN](#) is its primary method of sharing cleared information about urgent public health incidents with public information officers; federal, SLTT public health practitioners; clinicians; and public health laboratories. CDC’s HAN is a national program that directly and indirectly transmits health alerts, advisories, updates, and info services to more than one million recipients.

Data, Information, and Technology

Providers can use the data and information sources found in [Appendix E](#), in addition to any new real-time data specific to the emergency, to monitor emergencies and assess the impacts on CYSHCN and their families/caregivers. Providers may use data to:

- **Prevent Disruptions in Care:** When experiencing a medical surge, providers may use a system, such as the [STARS](#) system or other health information exchange systems (HIEs), to access patients’ medical history. Access to health records can prevent gaps in individualized care plans and prevent disruptions in care. This is especially relevant in situations where a CYSHCN with

⁷⁹ Forum on Medical and Public Health Preparedness for Catastrophic Events; Board on Health Sciences Policy; Institute of Medicine. Preparedness, Response, and Recovery Considerations for Children and Families: Workshop Summary. Washington (DC): National Academies Press (US); 2014 Mar 21. 4, Augmenting State and Local Emergency Plans. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK195869/>

medical complexity receives care in a setting that is out of state or within a different health care system.

- **Ensure Equitable Distribution of Resources:** Using data sources, such as the U.S. Census Bureau's [My Community Explorer](#) and [EJScreen](#), providers can identify which communities may be disproportionately impacted and require more urgent support (e.g., transportation services). Providers may also use this information as well as information collected during and after an emergency (e.g., needs assessments) to advocate for allocation of resources and services to these communities.
- **Monitor Health Care Capacity:** During an emergency, the influx of patients to health care facilities can further strain health care delivery systems. Providers can work with SLTT governments and emergency planners to consider ways to identify medical surge and facility capacity, such as bed availability. Providers can use this information to refer CYSHCN and their families/caregivers to appropriate facilities. This information is particularly relevant for CYSHCN as they are at higher risk of experiencing adverse effects during an emergency. See [ASPR TRACIE's Healthcare Coalition Pediatric Surge Annex Template](#) for more information and resources on medical and pediatric surge planning.
- **Identify Behavioral Health Needs:** Providers can work together and with CBOs to identify where behavioral health services may be needed most acutely, such as emergency shelters or in communities that have more limited access to behavioral health care.⁸⁰

⁸⁰ NCTSN. [Building Community Resilience for Children and Families](#).

Response Considerations for Providers in Various Emergency Scenarios

Providers can consider specific actions that they can take during a response to address the needs of CYSHCN and their families/caregivers for a variety of emergency scenarios.

Table 6: 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 (e.g., influenza, COVID-19)	<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 dispensing MCM, distributing personal protective equipment (PPE), 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.
Localized Emergencies (e.g., disruption in municipal services such as water, natural gas, roads and transportation)	<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 Requiring Evacuation (e.g., hurricanes, wildfires)	<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, LGBQIA+, etc.) before, during, and after evacuation as this population may require additional services and support.

Emergency Scenario	Example Response Considerations for Providers of CYSHCN and their Families/Caregivers
Natural and Human-Caused Disasters Not Requiring Evacuation (e.g., industrial incidents, mass violence)	<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.

Response Tools and Resources

The following includes resources mentioned in Module 2, in addition to other relevant tools. HHS is not responsible for the availability or content of the resources provided, nor does HHS endorse, warrant, or guarantee the resources listed above. It is the responsibility of the user to determine the usefulness and applicability of the resources provided.

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

- [\(DHS\)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 \(AAP\)](#)
- [Disaster Technical Assistance Center \(DTAC\) \(SAMHSA\)](#)
- [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 \(SAMHSA\)](#)

Module 3. Recovery

Overall Considerations

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

CYSHCN and their families/caregivers may experience long-term effects after an emergency. These effects may be exacerbated by existing SDOH, especially for CYSHCN and their families/caregivers experiencing marginalization and systemic oppression. These impacts may include:

- Financial loss (e.g., loss of income or job) or additional financial burdens (e.g., rent, increased utility bills, caring for additional family members).
- Loss of health insurance due to relocation.
- Loss or instability of housing due to infrastructure damage, changes in housing affordability, etc.
- Long- or short-term physical health impacts

Providers can engage CYSHCN and their family/caregivers to discuss the support they need to recover and resume typical activities. For example, CYSHCN and their families/caregivers may request support:

- 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.
- Understanding and enrolling in available government assistance programs.
- Updating existing individual care plans (e.g., addition of specialty care to address new and/or worsened conditions).
- Resuming regularly scheduled services, such as meals aligned with dietary requirements, medical care, medicine intake, and interactions with specialists, and therapies (e.g., physical therapy, occupational therapy, speech pathology).
- Understanding and treating behavioral health challenges.

Key Study:

Greater Impact: How Disaster Affects People of Low Socioeconomic Status

According to SAMHSA's 2017 supplemental research bulletin, SAMHSA found that people with low socioeconomic status are more likely to suffer serious consequences from disasters and emergencies, including for example, property damage, homelessness, financial impacts, and injuries. People with low socioeconomic status are more likely to:

- Live in areas at high risk for disaster impacts.
- Suffer more injuries and lose their lives.
- Face difficulty obtaining aid and assistance.
- Experience housing and food insecurity following an emergency.
- Experience depression and posttraumatic stress.
- Experience more long-term physical health challenges.

- 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, such as shelters, alternate care settings (i.e., acute care facility), or other temporary living situations into safe, familiar spaces with families/caregivers.
- Connecting with partners that can assist with medical needs, relocation, housing, and employment.
- Accessing long-term recovery and support groups.
- Advocating for the restoration of places for recreation that are frequently used by children and youth, including playgrounds, parks, schools, childcare centers, and community centers.

Providers can also 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. These communities may have fewer resources and require additional assistance to support recovery.

During recovery, providers can engage with CYSHCN and their families/caregivers, in addition to family and youth-led organizations, to gather lessons learned and conduct after-action planning to mitigate the negative impacts of future emergencies on CYSHCN. Providers may also participate in planning activities to help advocate for the needs of CYSHCN and their families/caregivers in future emergencies.

Access to Care and Health Insurance Coverage

During recovery, CYSHCN and their families/caregivers may have access to programs and services that can help them maintain access to systems of care, even if re-located or evacuated out of state during the emergency. Providers can refer clients to appropriate systems of care (e.g., well-child visits, specialist visits, screenings, immunizations) and support CYSHCN and their families/caregivers in:

- **Navigating health insurance policies:** Providers can collaborate with their partners in SLTT government agencies, including state Medicaid/CHIP programs, to identify changes to health insurance coverage during recovery. Providers can share information and points of contact with CYSHCN and their families/caregivers and help identify which changes impact them directly. Providers can familiarize themselves with possible changes and amendments to insurance policies using 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](#) (CMS Medicaid Disaster Toolkit) and the [Center for Medicaid and CHIP \(CMSC\) Medicaid and CHIP Coverage Learning Collaborative Inventory of Medicaid and CHIP Flexibilities and Authorities in the Event of a Public Health Emergency or Disaster](#). Insurance policies vary from state-to-state and providers can contact their [state Medicaid agency](#) for more information. In some cases, providers may or may not know their Medicaid state agency point of contact, in which case providers may also reach out to their state’s [Title V office](#) or [CMS directly](#).

Key Study:
2019 National Survey of Children’s Health

Key findings from the [2019 National Survey of Children’s Health](#) include:

- Medicaid/CHIP cover almost half of all U.S. CYSHCN, and these children are more likely to be low-income, a member of a racial or ethnic minority group, and younger than those children covered by private insurance alone.
- CYSHCN covered by both Medicaid/CHIP and private insurance have the greatest health care needs.
- CYSHCN with Medicaid/CHIP only are more likely to have greater health needs compared to those with private insurance only.

- **Medicare, Medicaid, and CHIP Waivers:** The HHS Secretary may temporarily waive or modify certain Medicare (for dual-eligible beneficiaries), Medicaid, and CHIP requirements through various authorities, including section 1135 Waivers, such as conditions of participation or other certification, preapproval, or licensure requirements.⁸¹ For example, flexibilities introduced during the COVID-19 pandemic allowed states to extend eligibility for Medicaid/CHIP,⁸² and CMS issued temporary measures to make it easier for people enrolled in Medicare, Medicaid, and CHIP to receive medical care through telehealth services. Providers can find the latest information on non-COVID emergency CMS waivers [here](#), and can contact their state Medicaid agency for more information.
- **Medicaid Home & Community-Based Services (HCBS) Waivers:** Additionally, in some cases, states may waive or modify HCBS 1915(c) waivers, which provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. Providers can contact their state Medicaid agency for more information.
- **Retroactive Coverage:** In some cases, if a CYSHCN is temporarily living in a new state due to evacuation or temporary relocation, states can request a waiver so beneficiaries can remain enrolled, thus allowing the home state to pay for out of state Medicaid coverage.
- **Out-of-Network Coverage:** Private health insurance companies typically have limited out-of-network coverage policies. Following an emergency, however, CYSHCN and their families/caregivers may need to be seen by an out-of-network provider due to damage, relocation, or unavailable medical records or insurance documentation. Providers can help CYSHCN and their families/caregivers locate accurate information and points of contact to understand what is covered by health insurance policies during recovery. Additionally, state Medicaid agencies may waive or modify out-of-network requirements for people with Medicaid and CHIP enrollees. Contact your state Medicaid agency for more information

HEALTH INSURANCE RESOURCES

- [Sign Up for Medicaid or CHIP](#)
- [Sign Up for Marketplace Health](#)
- [Quick Guide to the Health Insurance Marketplace](#)
- [CMS Emergency Preparedness and Response Information and Resources](#)

- **Understanding and accessing safety net programs:** After an emergency, families may become newly eligible for safety net programs. [Disaster case managers](#) are temporary case management support often available after a federally declared disaster and may be able to help connect CYSHCN and their families/caregivers with safety net programs to meet their unmet needs. For more information on safety net programs, see [Module 2: Partnering at the State and National Level](#).
- **Replacing medication, DME, and devices:** Medication, DME, and devices (e.g., wheelchairs, feeding pumps, back-up equipment) may be lost or damaged during an emergency, such as during rapid evacuations or during a flooding event. During recovery, providers can support CYSHCN and their families/caregivers in contacting their state Medicaid agency to help them

⁸¹ CMS. [State Waivers List](#).

⁸² CMS. [Coronavirus Waivers](#).

**Story from the Field:
Florida Insurance Policies for Emergency
Drug Supplies**

Insurers in Florida typically restrict individuals from more than one prescription refill over a certain period of time. However, the Florida state government adopted [policies requiring all state-licensed health insurers to lift these restrictions](#) during emergencies. This allows individuals living in counties with declared emergencies to receive a 30-day supply of prescription drugs regardless of the date of their last refill. In addition, Florida Medicaid policy offers coverage for [up to two 72-hour emergency supplies of prescription drugs](#) over 30 days.

determine whether their insurance plan allows for replacement or requires new prescriptions for replacement DME and/or back up equipment. State Medicaid agencies can also help determine if their plan covers the cost of replacing DME and other medical supplies after a re-location or prolonged emergency.⁸³ Some states also maintain [funding](#) programs for assistive technology devices and services, to help make them more accessible and available.

The Emergency Prescription Assistance Program (EPAP) helps people in federally-declared disaster areas who do not have health insurance get the prescription drugs, vaccinations, medical supplies, and equipment that they need.⁸⁴ EPAP only covers certain prescription medications and DME. To find out whether the CYSHCN's medication and/or DME is covered, please see [Items Covered by EPAP](#). Providers can [see if EPAP has been activated in their area](#) and can assist CYSHCN and their families/caregivers in filing a claim.

- **Resuming regular provider visits:** Providers can support CYSHCN and their families/caregivers in identifying and scheduling appointments (in-person or virtually) for individuals who may have missed immunizations, therapies, or other important visits due to the emergency. Providers are key partners during this process for CYSHCN who may have required hospitalization during an emergency and need immediate follow up care.

Transition from Temporary Settings

In situations where CYSHCN relocated to temporary or acute care settings, providers can help ensure they are discharged appropriately and able to return to their original systems of care, or a comparable setting where they can live in the most appropriate and least restrictive setting. Review [Module 1: Individuals, Families, Caregivers, and Systems of Care](#), for more information on preparing a discharge plan. Prior to discharge, providers can use the CMIST framework for person- and family-centered care, which includes assessing follow-up needs and identifying available resources and community services:

- **Communication:** Ensure availability of appropriate resources for communicating effectively, including interpretation services for CYSHCN and their families/caregivers with LEP, auxiliary speech or hearing devices (e.g., hearing aids) for those who are deaf or hard-of-hearing, and written materials that convey necessary information in plain language (in multiple languages or in Braille).
- **Maintaining Health:** Identify any additional needs or forms of assistance (e.g., support in transitioning to or from virtual services) for CYSHCN who rely on HCBS or long-term services and supports (LTSS) and connect them to these services. Collaborate with CYSHCN and their families/caregivers to update their individualized care plan prior to discharge from an acute care or other in-patient setting, which may include ensuring access to appropriate medications or other therapeutics.

⁸³ ASPR TRACIE. [Durable Medical Equipment in Disasters](#).

⁸⁴ ASPR. [The Emergency Prescription Assistance Program](#)

- **Independence:** Collaborate with CYSHCN and their families/caregivers to identify new or replacement mobility devices and other DME (e.g., ventilators), that will allow CYSHCN to remain at home supported by their system of care. Share information on, and support for, replacing any equipment and/or device that was lost or damaged in the emergency (e.g., an individual’s specific state Medicaid policies on replacing lost or damaged DME), and work with CYSHCN and their families/caregivers to identify and secure accommodations or additional services so that they can return to school.
- **Support and Safety:** Support CYSHCN and their families/caregivers who may experience a change in their needs for resources and support and an increase in anxiety or other psychological distress because of the events they witnessed and experienced in an emergency. Provide referrals for culturally competent behavioral health services and other supports (e.g., school-based services) when available. Support CYSHCN in connecting with caregivers and support family/caregivers by providing information and resources they need to meet the support and safety needs of CYSHCN.
- **Transportation:** Connect CYSHCN and their families/caregivers to assisted and accessible transportation and transportation support services (e.g., transportation to school and medical appointments) that support their independence following discharge from an acute care or other in-patient setting, such as accommodations for DME, mobility devices, or service animals.

Behavioral Health and Trauma-Informed Approaches During Recovery

CYSHCN and their families/caregivers may have experienced an evacuation, a life-threatening situation, loss of a loved one, or even witnessed a death. Challenges coping after these types of events are common. The additional disruptions in usual routines and difficulty accessing systems of care make it hard to get needed support.^{85,86} Because of the disproportionate effects of emergencies on communities experiencing adverse SDOH, behavioral health impacts are often multifactorial and compounded, while resources for behavioral health services are fewer.

A trauma-informed approach can help CYSHCN feel safe and supported during recovery. Providers can work together to implement person- and family-centered care that involves CYSHCN and their families/caregivers. They can also increase social support networks from the CSHCN’s broader community. Providers can connect CYSHCN with appropriate supports, apply CLAS standards ([Module 1](#)) to communication and treatment, and ensure equitable access to behavioral health services.

Providers can collaborate with partners (e.g., behavioral health professionals, SLTT government, CBOs) to help CYSHCN address their behavioral health needs during recovery. Examples of collaboration include:

- Work with behavioral health systems of care to identify culturally appropriate strategies to address ongoing behavioral health screening, surveillance, and treatment needs.
- Increase the behavioral health support that is available for CYSHCN and their families/caregivers.
- Share information on support for people in suicidal crisis or emotional distress, such as [SAMHSA’s 988 Suicide and Crisis Lifeline](#).

⁸⁵ CDC. [Children’s Emergency Preparedness: Why CDC Makes It a Priority](#).

⁸⁶ CDC. [Keeping Children with Disabilities Safe in Emergencies](#).

- Identify geographic areas that lack sufficient behavioral health services and identify opportunities to deploy professionals, augment using mobile health services, or utilize telehealth, as appropriate.
- Facilitate opportunities for CYSHCN and their families/caregivers to participate in creative outlets that can play a role in coping and recovery for youth.

Partnerships and Coordination

Providers can continue to coordinate with partners identified in [Module 1: Partnerships and Coordination](#) and [Appendix G](#) during recovery to help support the needs of CYSHCN and their families/caregivers.

Partnering with Providers

During recovery, it is critical for providers who are part of CYSHCN’s systems of care to continue a high level of communication and coordination to address ongoing needs and resources. Providers may collaborate to:

- Identify alternate access to health care services (e.g., CYSHCN who require physical or occupational therapy may have these services shifted to their homes from outpatient centers).
- Local [Disability Networks](#) may be able to assist with supporting CYSHCN and their families/caregivers in making decisions about LTSS.
- Update medical records with information that may have changed during an emergency (e.g., new medication provided, new address, new or changed services).
- Transition data from acute care providers into medical records (e.g., a CYSHCN received care in an acute care facility during the emergency, or there was significant disruption to recordkeeping during the emergency). When transitioning relevant information to patient portals or to other specialists, providers can follow established quality assurance processes to ensure the completeness and accuracy of patient records and data and prevent further disruptions to care.
- 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.

Partnering with Community-Based and Consumer Directed Organizations

CYSHCN and their families/caregivers rely on the systems in which they receive care and resources, including schools, health care, cultural/religious centers, and community centers. Providers can continue to collaborate with CBOs to provide long-term recovery resources to CYSHCN and their families/caregivers.

In addition, after an emergency, CBOs often join together to support [Long Term Recovery Groups \(LTRG\)](#), which provide valuable support following an emergency and can connect survivors with resources, such as grants, food and clothing assistance, and support recovery projects, such as rebuilding and clean-up. LTRGs are typically formed by Voluntary Organizations Active in Disaster (VOAD) or County (local) Organizations Active in Disaster groups to coordinate between agencies providing long term recovery human and health services.

Partnering with Schools

During emergencies, schools and other recreational activities may experience disruption, temporary closure, or shifts to virtual services. Schools are a trusted entity and play an important role in disaster recovery for CYSHCN and their families/caregivers. They provide a space for healing, including through the provision of behavioral health services, and enable CYSHCN to regain a sense of normalcy.⁸⁷ During recovery, providers and their partners can collaborate with school administrations and 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 a plan in the least disruptive and most effective manner. For example, providers and their partners may:

- Resume school-based services, such as therapies included in a CYSHCN's IEP or IAP, for continuity of support to learn and thrive. See [Module 1: Partnering with Schools](#) for more information.
- Provide information, resources, and training to educators, families, and caregivers on physical and behavioral health needs of CYSHCN that may be relevant during the recovery phase.
- Use schools as a hub for identifying and sharing resources. For providers, this may include working with educators to assist in performing needs assessments to identify emergent needs for CYSHCN and their families/caregivers following an emergency.
- Use school buildings for the provision of services to address behavioral health needs, such as contracting with school personnel to provide additional therapies/support after school hours, and usage of school buses to transport families to health care appointments.

Story from the Field: Schools as a Resource Hub

In Puerto Rico after Hurricane Maria, schools were no longer acting as shelters, but still served as hubs for sharing resources, providing behavioral health services, and identifying community needs.

Partnering at the State and National Level

Depending on the size and scale of the emergency, providers may work with SLTT and federal agencies through the [ASPR Division of Community Mitigation and Recovery](#). ASPR's Division of Community Mitigation and Recovery coordinates federal and state assistance to local community-led recovery efforts that restore and improve public health, health care, and social service networks while promoting the resilience, physical and behavioral health, independence, and well-being of individuals and communities affected by disasters and health emergencies.⁸⁸

Continuity of Operations

During recovery, providers can focus on returning to normal operations, such as re-opening facilities or returning to in-person visits and may take steps to learn from the emergency. Providers may consider the following activities:

- **After Action:** Conduct an after-action review to identify areas for improvement and incorporate lessons learned into COOP plans.
- **Workforce:** Consider impacts to the provider workforce from burnout and attrition caused by changes in provider workflows. This may exacerbate existing workforce shortages and be due to increased needs of services; a decrease of availability of providers due to evacuation,

⁸⁷ SAMHSA. [Disaster Technical Assistance Center Supplemental Research Bulletin Behavioral Health Conditions in Children and Youth Exposed to Natural Disasters](#).

⁸⁸ HHS ASPR. [Health and Social Services Recovery Support Function](#).

relocations, and damaged infrastructure; as well as ongoing disruptions to the systems of care. These factors contribute to additional strain on the scarce workforce, which provides challenges for CYSHCN and their families/caregivers in access to care.

Communication

During the recovery phase, providers can focus on communication messages that are geared towards addressing community resilience, promoting emotional well-being, and reducing any community-specific stigma, structural inequities, and other challenges with accessing systems of care.^{89,90} As with all communication throughout the emergency management cycle, messages should be clear, easy to understand, and culturally and linguistically appropriate (see [Module 1: Preparedness, Communication](#)).

Communication among providers and CYSHCN and their families/caregivers should be bi-directional and assess status of CYSHCN and their families/caregivers, identify unmet needs, make referrals, and provide information. Providers may share, for example, relevant and timely information on the following topics:

- The resumption of health care services that may have been paused during an emergency.
- 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

When supporting recovery efforts, providers and their partners can consider how data may help provide equitable support to CYSHCN and their families/caregivers. Providers may use data during recovery to:

- **Promote Equity and Informed Decision-Making:** Providers can use data to better understand communities disproportionately affected by the emergency, identify where long-term recovery resources may be needed, and promote changes towards more equitable policies. ([Module 1: Data, Information and Technology](#) and [Appendix E](#))
- **Resume Routine Care:** As discussed in [Module 2: Data, Information, and Technology](#), systems such as STARS and HIEs provide valuable data and information for CYSHCN. These systems can help providers identify gaps, changes, and challenges in care that may have occurred during an emergency when CYSHCN transition back to their regular systems of care.
- **Evaluate and Continue the Distribution of Equitable Resources:** Using previously identified data sources, such as the U.S. Census Bureau's [My Community Explorer](#), [Census Advancing Data Equity Tools](#), and [EJScreen](#), providers can identify which communities may be disproportionately impacted and require more urgent and/or dedicated support following an emergency. Providers may also use this information to advocate for allocation of resources and services to these communities that may strengthen community resilience and mitigation efforts during the recovery process.
- **Monitor Health Care Capacity:** Following an emergency, an influx of patients to health care facilities may have caused additional burden to already strained systems. Providers can continue to report and use data to identify which facilities have returned to pre-emergency bed capacity

⁸⁹ NCTSN. [Creating Trauma-Informed Systems](#).

⁹⁰ NCTSN. [Building Community Resilience for Children and Families](#).

and an adequate workforce. This information is significant for CYSHCN and their families/caregivers as they may need to continue to use health care facilities during recovery.

- **Identify Behavioral Health Needs and Continue to Provide Services:** Providers can use privacy protected data from call centers, +211, +311, +911 dispatch, +988, and other resources to help determine where behavioral health and social services may be needed following an emergency. This information can help establish more permanent services and identify communities that have limited access to behavioral health care.⁹¹
- **Measure Community Resilience:** Communities are beginning to measure community resilience through commonly used indicators, such as educational attainment, unemployment rate, disability, English language proficiency, age, health insurance, hospital capacity, connection to civic and social organizations, public school capacity, and more. Providers can coordinate with partners to determine indicators for their community and use complementary data sources ([Module 1: Data, Information and Technology](#) and [Appendix E](#)) to determine the current level of community resilience and SDOH for CYSHCN and their families/caregivers in the community. They may also combine this information with data from other tools, such as the [FEMA Resilience Analysis and Planning Tool \(RAPT\)](#).^{92,93} Providers may also choose to use the trauma-informed [Communities Advancing Resilience Toolkit](#), which is a “community intervention designed to improve community resilience through assessment, education, empowerment, teamwork, and action.”

Mitigation and Community Resilience

Mitigation and community resilience often includes ongoing actions taken following the recovery phase to reduce or eliminate long-term risks from emergencies. It expands on traditional emergency planning by promoting strong community systems and eliminating disparities around SDOH that make some CYSHCN less resilient and more at-risk for adverse impacts from emergencies. Providers can elevate the voices of CYSHCN and their families/caregivers and encourage active participation in shared decision-making as their community seeks to build resilience. Mitigation and resilience activities are ongoing, and often concurrent to other emergency preparedness, response, and recovery activities. To mitigate risks and build resilience, providers, CYSHCN, their families/caregivers, and other partners, can collaborate to:

- **Data:** Increase access to data among the community, providers, and partners that can be used to identify and inform strategies to address adverse SDOH and eliminate disparities. Review [Module 1: Data, Information and Technology](#) and [Appendix E](#) for data sources to support this activity
- **Awareness and Investment:** Increase awareness about the hazards and risks in their community, such as those caused by climate change, that more acutely impact CYSHCN and their families/caregivers. Then, collectively work toward improving and initiating programs and policies that address gaps in local services for CYSHCN and their families/caregivers, particularly those who are medically underserved.
- **Community Resilience and Mitigation:** Identify a community resilience and mitigation strategy to guide decisions, build resilience, and address SDOH by strengthening and promoting access to services and supports. Identify actions that will reduce risks from all hazard threats, and increase local capacity, social support, resources and ensure equitable investments into the community.

⁹¹ NCTSN. [Building Community Resilience for Children and Families](#).

⁹² RAPT is an interactive map that displays county and census tract-level data layers on 20 community resilience indicators, infrastructure, hazard, real-time weather, and predicted risk of emergencies.

⁹³ FEMA. [Community Resilience Indicator Analysis: County-Level Analysis of Commonly Used Indicators from Peer-Reviewed Research](#).

- **Policy Changes:** Work with partners to implement and evaluate the effectiveness of policy changes (e.g., telehealth, enrollment flexibilities), programs, requirements, and funding and advocate for permanent policy changes where beneficial for CYSHCN and their families/caregivers and to promote equity.
- **Trust:** Continue to build and foster trust with CYSHCN and their families/caregivers who are disconnected from traditional systems of care (see [Module 1: Individuals, Families, Caregivers, and Systems of Care](#)), including building social connectedness, expanding collaboration outside of typical partners, and strengthening day-to-day systems that support health.

LESSONS LEARNED FROM THE COVID-19 PANDEMIC

The unusually prolonged and protracted nature of the COVID-19 pandemic, in addition to the more frequent and costly natural and human-caused disasters, have required a greater shift to conducting concurrent emergency preparedness, response, recovery, and mitigation/community resilience activities. The COVID-19 pandemic revealed new and emphasized outstanding challenges in emergency planning, such as increased and frequently changing response needs, provider burnout, and prolonged disruptions to institutions that are meant intended to protect CYSHCN. Key lessons learned from the COVID-19 pandemic that inform mitigation and community resilience for CYSHCN include:

- **Adaptable systems of care and referral mechanisms** are needed during emergencies to support CYSHCN and their families/caregivers who rely on home and community-based services supported by home health providers and telehealth.
- **Early engagement and long-term investment** in primary health care systems and community health care workers are needed, as they play vital roles in response and contribute to the overall resilience of communities.
- **Behavioral health services** are an integral part of the emergency management cycle, from planning to response to community resilience. Engagement of partners is needed to reach CYSHCN and their families/caregivers and to address a wide range of psychosocial issues. Behavioral health services are also important to promote workforce resilience, as providers experienced a high level of burnout and behavioral health challenges during the COVID-19 pandemic.
- **Health equity and addressing adverse SDOH** are foundational components of community resilience and should be prioritized across emergency planning. Populations experiencing inequity will likely be disproportionately impacted by emergencies.

Climate Resilience

Climate resilience refers to the capacity of an individual, community, or institution to understand potential climate impacts and respond dynamically and effectively to shifting climate circumstances and events.⁹⁴ The extent to which communities are impacted by climate change, and the speed at which they can positively adapt, depends on “socioeconomic status, the condition and accessibility of infrastructure, the accessibility of health care, specific demographic characteristics, and other resources.”⁹⁵ Populations that are more likely to be negatively impacted by climate change those that experience other disparities due to social determinants of health and marginalization, which include but are not limited to low income communities, immigrant groups (including those with LEP), AI/AN, children, people with disabilities, and people with pre-existing or chronic medical conditions.⁹⁶

The health impacts of climate change on CYSHCN and their families/caregivers may include an increase in⁹⁷ heat-related illnesses and death, asthma attacks, allergies, and respiratory infections, foodborne and waterborne illness, and trauma and behavioral health impacts, such as anxiety, depression, and post-traumatic stress due to multiple, recurring stressors (e.g., yearly wildfires or hurricanes) or protracted crises (e.g., COVID-19, extreme heat).

⁹⁴ HHS. [Primary Protection: Enhancing Health Care Resilience for a Changing Climate](#).

⁹⁵ EPA. [Climate Change and Social Vulnerability in the United States](#).

⁹⁶ HHS Office of Climate Change and Health Equity. [Climate Change and Health Equity](#).

⁹⁷ U.S. Global Climate Change Research Program. [The U.S. Climate Resilience Toolkit](#).

In addition, extreme weather events, such as flooding, tornadoes, wildfires, and extreme heat or cold, may impact important aspects of the life of a CYSHCN and their families/caregivers. These include, but are not limited to:

- Damaged or closed facilities including schools, spaces for recreation, places of worship, community centers, libraries, pharmacies, and health care facilities.
- Disruption to systems of care (e.g., physical therapy, behavioral health, food assistance programs), magnifying the stresses that CYSHCN and their families/caregivers already face in an emergency.
- Damage to infrastructure, including roads, electrical grid, water systems, internet. Loss of power may be particularly challenging for CYSHCN with electricity-dependent DME and devices.
- Disruption to transportation, including public transit, emergency vehicles, and assisted and accessible transportation. This is especially challenging in rural areas where there may be little to no redundancy in the transportation infrastructure, which could lead to adverse health outcomes for CYSHCN and their families/caregivers if they are unable to reach providers and other needed services.
- Financial instability due to rising temperatures and increased utility bills.
- Negative impact on critical infrastructure and traditional livelihoods for indigenous communities, threatening access to traditional foods, and forcing some communities to relocate to higher ground.⁹⁸

Providers can consider the following actions to promote climate resilience and can learn more about what action steps can be taken through [ASPR's Climate Change Resilience Healthcare Systems Considerations](#):

- Invite CYSHCN and their families/caregivers to get involved in mitigation and resilience efforts,⁹⁹ such as the activities described in the “Stories from the Field: Youth Activism for Climate Resilience” box.
- Identify potential hazards and health outcomes, estimate the disease burden, and identify interventions that will help reduce the negative impacts of climate change on the health of CYSHCN and their families/caregivers, using frameworks such as CDC’s Building Resilience Against Climate Effects (BRACE) Framework ([Appendix M](#)).
- Identify and address limitations of public policy, community infrastructure challenges, assess vulnerabilities, and create facility specific mitigation plans. For example, providers may work with

Stories from the Field: Youth Activism for Climate Resilience

Navajo Nation: Hotter, Drier Climate Puts Sand Dunes on the Move:

The U.S. Geological Survey Hydrologic Extremes and Aeolian Ecosystems on Tribal Lands Project includes a pilot project in partnership with the Navajo Youth Conservation Corps to mitigate climate change impacts on dune movement.

Students Design Low-Impact Landscape to Reduce Stormwater

Runoff: High school students in Kentucky became proficient in using the EPA's Stormwater Calculator and put those skills to work when their county planned a new library.

Where Do We Need Shade? Mapping Urban Heat Islands in

Richmond, Virginia: Citizen-scientists, including youth, used specially equipped bikes and cars to find out where it’s hottest—and where residents might be most vulnerable to extreme urban heat.

Students Promote Flood Resilience and Reduce Insurance Costs:

Middle school students are working to help residents recognize and reduce flood risk in their coastal Georgia city. Their efforts are also earning the community credits to lower their costs for flood insurance.

⁹⁸ U.S. Global Climate Change Research Program. [The U.S. Climate Resilience Toolkit: Tribal Nations](#).

⁹⁹ Gislason, M. K., Kennedy, A. M., & Witham, S. M. (2021). [The Interplay between Social and Ecological Determinants of Mental Health for Children and Youth in the Climate Crisis](#). International journal of environmental research and public health, 18(9), 4573. <https://doi.org/10.3390/ijerph18094573>

their partners to use [the EPA Indoor Air Quality \(IAQ\) Tools for Schools Program](#) to prevent health problems triggered by an increasing number of IAQ issues due to climate change (e.g., wildfire smoke).

- Promote equity and [environmental justice](#), which is the fair treatment and meaningful involvement of all people and ensures the same degree of protection from environmental and health hazards and equal access to the decision-making process.¹⁰⁰

¹⁰⁰ EPA. [Environmental Justice](#).

Recovery Considerations for Providers in Various Emergency Scenarios

Providers may consider specific actions that they can take during recovery to address the needs of CYSHCN and their families/caregivers for a variety of emergency scenarios.

Table 6: 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 (e.g., influenza, COVID-19)	<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 circumstances and risks should occur one-on-one between providers and CYSHCN and their families/caregivers. • 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 (e.g., disruption in municipal services such as water, natural gas, roads, and transportation)	<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 (e.g., hurricanes, wildfires)	<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.
Natural and Human-Caused Disasters Not Requiring Evacuation (e.g., industrial incidents, acts of terrorism, mass violence)	<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.

Recovery Tools and Resources

The following includes resources mentioned in Module 3, in addition to other relevant tools. HHS is not responsible for the availability or content of the resources provided, nor does HHS endorse, warrant, or guarantee the resources listed above. It is the responsibility of the user to determine the usefulness and applicability of the resources provided.

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 \(Terrorism and Disaster Center\)](#)
- [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 \(U.S. Global Climate Change Research Program\)](#)

Module 4: Case Studies

Case Study 1

Jack, 8-year-old with Autism diagnosis



Biography:

- 8 years old
- Lives with his parents and older brother in a single-family home in a small town
- Attends a local elementary school and loves math
- Has an older brother who helps care for him

Conditions and Challenges:

- Autism diagnosis and seizure disorder, managed by anti-epileptic medicine
- Has an Individualized Education Plan (IEP) and receives specialized in-classroom support and individualized behavioral and occupational therapies
- Manages anxiousness with an educational video game and a curated playlist of his favorite music

Preparedness: Jack's pediatric provider, teacher, classroom aide, and therapists work with him and his family to create an emergency plan, including key considerations related to his special health care needs. As part of this plan, Jack's family creates an emergency kit to keep in the nurse's office at school. It includes his emergency information form with relevant health information; family and provider contact information; non-perishable snacks; and personal items (e.g., noise cancelling headphones, fidget toys).

In the event of an emergency, Jack's pediatric provider wrote a prescription for additional anti-epileptic medication. Unfortunately, his insurance denied the request and Jack was unable to receive the additional supply of medication to keep in the emergency kit. Jack's parents enrolled in the county and school auto-alert voice call and text messaging service in case of emergencies or school closures, as required by the school district.

Emergency Scenario: *It started as a typical rainy day when Jack went to school. At 11:00 am, the rain intensified, and there was a flash flood warning. The county issued an immediate mandatory evacuation of the elementary school and surrounding area.*

Response: Jack's classroom aide retrieves his emergency kit from the nurse's office as his class prepares to evacuate to a shelter that is on higher ground and outside the potential flash flood zone. Jack's parents receive auto-alert text messages and a call from Jack's school with the location of the evacuation shelter. Jack's parents quickly evacuate to the same shelter. When his parents arrive, they find Jack anxious and overstimulated. Jack's brother's school is not located in a flood zone, so he does not evacuate and stays with a friend while his family is in the shelter. Jack's parents ask the staff for a quiet room to help Jack manage his behavioral response. Unfortunately, the shelter does not have a designated quiet room. Jack's parents find a less-crowded corner of the shelter and help Jack cope by using the noise cancelling headphones and other fidget toys from the emergency kit.

Recovery. After twelve hours, the flood water recedes and Jack's family leaves the shelter, picks up his brother from the friend's house, and returns to their home. They find their basement flooded, but the rest of their home remains undamaged. Unfortunately, Jack's school cannot re-open due to flood damage, and his elementary school must plan to temporarily share space with another elementary school that was not affected.

As Jack plans to return to school at the temporary location, he struggles with anxiety. His parents, teacher, and classroom aide coordinate with the school-based counselor to discuss strategies to help manage his anxiety and re-establish his routine. Together they plan a video call with his teacher, classroom aide, and the school counselor to reassure him that though school will be held in a different place, the structure of his day and the people he interacts with will be the same. These efforts help Jack and his family resume their normal routines after the emergency.

Case Study 1- Further Reflection

What elements in this case helped to make the emergency response successful?

Potential Responses:

- Prior to the evacuation, Jack's providers work with him and his family to develop an emergency kit to ensure access to the medical information, necessary items, and supplies in case of a future emergency. See [Module 1: Preparedness - Individuals, Families, Caregivers, and Systems of Care](#).
- The auto-alert system notifies Jack's parents of the school evacuation in a timely manner, allowing them to locate Jack and evacuate to the same shelter to be with Jack. See [Module 1: Preparedness – Partnerships and Coordination](#).
- Upon return home, Jack is anxious about the temporary school. His parents, provider, teacher, classroom aide, and therapists quickly work together to address Jack's fears, provide reassurance, and offer him some control over his new environment. See [Module 3: Recovery – Partnerships and Coordination](#).

What could be improved in this scenario?

Potential Responses:

- Initially, shelter staff were unable to offer accommodations to support Jack's needs. While his parents were able to help him cope, if he had become overwhelmed, he may have had a temporarily loss of control or meltdown. Shelter planning may have considered setting aside a quiet area available for people who need a low-stimulation environment (e.g., people with autism, dementia, mental health needs, etc.). See [Module 1: Preparedness - Partnerships and Coordination](#).
- Although Jack's pediatrician provides the additional prescription for medication for Jack, the insurance company denies the emergency supply of anti-epileptic medication to manage Jack's seizure disorder. Having additional medication on hand would benefit Jack in the event of a prolonged shelter stay. See [Module 3: Recovery - Individuals, Families, Caregivers, and Systems of Care](#).

Case Study 2

Rita, 13-year-old with medical complexity



Biography:

- 13 years old
- A rising 7th grader, who loves school
- Participates in a district-wide acting summer camp to elevate the voices of youth with cerebral palsy and challenge perceptions about people affected by neuromuscular conditions
- Lives with her mother, who works at a restaurant and is the primary financial provider, and her grandmother in a first-floor apartment that is wheelchair accessible

Conditions and Challenges:

- Is a “former preemie,” and has resulting medical complexity, including cerebral palsy
- Uses a motorized wheelchair for mobility
- Relies on a feeding tube for nutrition and uses a tablet as an augmented and alternative communication device (AAC) as her swallow and speech are affected
- Receives her primary care from her local pediatric office and specialized coordinated care in the CYSHCN complex medical program at a large children’s hospital that is two hours away
- Insured by her state Medicaid program through a local Medicaid Managed Care Organization (MMCO), who has maximized in-home supports through a home health aide to keep Rita healthy, mobile, and independent

Preparedness: Rita’s primary care and specialty care team discussed with Rita and her family the potential actions they can take to prepare for emergencies, such as putting together an emergency kit in case they need to evacuate to a shelter. However, no action has been taken at this time.

Emergency Scenario: *The county issues a heat advisory, anticipating consecutive days of temperatures above 100° F. The electrical grid crashes, resulting in a power outage to the family’s apartment. Local officials encourage residents to shelter-in-place.*

Response: Rita's family shelters-in-place in their apartment for two days. Rita’s home health aide continues to visit daily to help Rita with her assisted feeding and activities of daily living. Rita’s wheelchair battery eventually runs out, leaving her without a mobility device. After two hot days, Rita shares that she doesn’t feel well. Together, Rita, her mother, and her home health aide call her pediatrician, who agrees that Rita should be assessed in an emergency department. Rita’s home health aide calls 911 for emergency transportation to the nearest hospital emergency department, because the children’s hospital is too far away.

At the hospital, the emergency department staff find that Rita’s pediatrician’s electronic medical records are not linked to those in the hospital system. They call the pediatrician, who shares relevant medical history, and agrees to transfer her medical records to the hospital first thing when the office opens the next day. The emergency department staff admit Rita to the inpatient pediatric care unit.

Recovery: At the hospital, Rita is treated for dehydration and urinary tract infection for three days. Given Rita’s medical complexity, her hospital providers collaborate closely with her pediatrician prior to discharge to ensure a smooth transition home. The hospital staff also work her MMCO case manager to arrange for Medicaid pre-authorization for her transportation home from the hospital to the family’s apartment, where power has been restored.

Unfortunately, Rita's mother is not given any shifts at work for the following two weeks because of her recent absences to care for her daughter, resulting in a depletion of the family's financial resources and the difficult decision of choosing which necessity to pay for: electricity or food. Rita's mother speaks to Rita's primary care provider to receive medical certification to receive help with her electric bills and avoid having their electricity cut off, and she reaches out to a local nonprofit organization to gain access to a financial assistance program that may provide interim help with rent and link her to food bank resources. Over the next few weeks, Rita's mother resumes her typical work schedule and the family transitions back into their system of care and normal routines.

Case Study 2- Further Reflection

What elements in this case helped to make the emergency response successful?

Potential Responses:

- Rita's transition home from the inpatient pediatric unit went smoothly, in part due the coordination between her pediatrician, the hospital staff, and her care coordinator. See [Module 3: Recovery - Partnerships and Coordination](#).
- Rita's care team and MMCO case manager were able to recognize the needs of the family and offered resources to assist in times of need. See [Module 3: Recovery - Partnerships and Coordination](#).

What could be improved in this scenario?

Potential Responses:

- To mitigate the consequences of losing power, Rita's system of care providers could have contacted the local public health and emergency management department to identify cooling center locations and appropriate transportation. In addition, Rita, her family, and system of care providers should determine if there is a local registry for high risk medically dependent individuals so that first responders can contact, locate, assess, and prioritize her care. See [Module 1: Preparedness: Individuals, Caregivers, and Systems of Care](#).
- While it was helpful that Rita's doctor communicated with the hospital, Rita would have benefited from a having an emergency information form with a detailed care plan that could have been shared among her providers to facilitate her care and prevent delays. See [Module 1: Preparedness: Individuals, Caregivers, and Systems of Care](#).
- The challenges of seeking hospital care outside her normal system of care could have resulted in a more medical complications requiring a longer acute care stay. If Rita were a part of a program, such as Special Needs Tracking and Awareness Response System (STARS), or had a medical home, this transition may have been smoother resulting in increased access to pertinent information and continuity of care. See [Module 1: Preparedness – Data, Information, and Technology](#).

Case Study 3

Amber, 15-years-old with sickle cell disease



Biography:

- 15 years old
- Lives with her parents and her younger brother in a large city
- Attends 10th grade at her local high school, where she is on student council and dances on her high school's drill team

Conditions and Challenges:

- Lives with sickle cell disease and, at 12-years-old, experienced a stroke, but had no lasting physical or cognitive effects
- Has close relationship with both her primary care provider and her hematology team at her local children's hospital, where she receives a specific medication and a blood transfusion every five weeks to prevent another stroke
- Understands the importance of staying well hydrated to avoid triggering a sickle cell crisis

Preparedness: Given their strong partnership with her care team, Amber and her family are well-informed about her sickle cell disease and received resources highlighting when to call her health care team or go to an emergency room for evaluation. Amber registered with the community's emergency medical tracking system for CYSHCN. Amber's parents are active in a sickle cell disease parent group led by her specialty care team. Amber is afraid of being stigmatized and does not disclose her diagnosis to anyone at her high school.

Emergency Scenario: *Two weeks into Amber's school year, the city's water source is contaminated with a potentially dangerous parasite and orders an immediate boil water advisory. The city encourages residents to use bottled water and anticipates it may take several weeks to resolve.*

Response: Because of Amber's sickle cell disease, she has an increased risk of parasitic infection. Amber's family goes to the local grocery store but are only able to obtain one case of water due to a limited supply. Given the lack of bottled water, the family begins to worry, wanting to make sure everyone, especially Amber, has access to clean water to remain hydrated. Amber's school remains open and works to provide students with access clean water, but resources are limited. The next day at school, Amber becomes busy with her activities and does not drink enough clean water.

During drill team practice, she starts to feel lightheaded and nauseous. Amber tells the new school nurse that she is not feeling well and has a history of a stroke. The nurse calls emergency services. Upon arrival, EMS accesses the emergency medical tracking system for Amber's emergency care plan, and they quickly collaborate with her care team at the children's hospital to expedite care. Amber is transported to the children's hospital, where she is treated for dehydration.

Recovery: Within one day, Amber's bloodwork and vitals return to normal. Because the boil water advisory is ongoing, her care team shares water distribution sites with Amber and her family. Unfortunately, the distribution sites are far from where Amber and her family live. They have difficulty finding time away from work and school to make the long trip to the distribution site on public transportation, as they do not have a car and cannot afford private transportation.

Upon returning home, Amber fears that she may not have access to water and that she could have another stroke. In the weeks after, Amber begins to withdraw from her school activities and to occasionally skip school. Amber's parents notice her changed behavior and ask her to share her concerns with her health care team. The care team reminds Amber that she is on a transfusion protocol

that is protecting her from the risk of another stroke, and they recommend for her to participate in a sickle cell disease teen group led by a social worker.

Case Study 3 - Further Reflection

What elements in this case helped to make the emergency response successful?

Potential Responses:

- Given Amber and her family's collaborative relationship with her care team, Amber and her family are well-educated and aware of her medical condition. See [Module 1: Preparedness: Individuals, Families, Caregivers, and Systems of Care](#).
- Because Amber registered with the emergency medical tracking system for children with medical complexity in her community, EMS and providers were able to quickly identify Amber's needs and expedite medical care upon arrival at the hospital. See [Module 1: Preparedness: Individuals, Families, Caregivers, and Systems of Care](#).

What could be improved in this scenario?

Potential Responses:

- If Amber's school had a better approach for identifying and monitoring CYSHCN, the school could ensure accommodations so that Amber has sufficient access clean water. See [Module 2: Response – Partnerships and Coordination](#).
- The water distribution sites were located far away from Amber's neighborhood. Providers may consider how to advocate for more equitable distribution of resources. See [Module 3: Recovery – Data, Information, and Technology](#).
- Amber's family would have benefited from identifying additional resources or referral to assistance programs to access clean water sources due to the amount of time and money spent obtaining water. See [Module 1: Preparedness – Partnerships and Coordination](#).

Appendix A: Overview of the Emergency Management Cycle

The emergency management cycle is a four-step, crosscutting approach that can be used across Federal and SLTT for a broad range of emergencies, including localized emergencies, natural disasters, human-caused disasters, and infectious disease outbreaks. Below are the phases of the emergency management cycle.

Term	Definition
Preparedness	The Preparedness phase of the emergency management cycle includes continuous dedication of time and resources for adequate planning, organizing, education, evaluation, and training, especially for events that cannot be mitigated. The preparedness phase typically occurs before an emergency. Examples of preparedness activities include creating emergency preparedness plans and resources sheets, conducting drills, tabletop, and full-scale exercises, identifying, and storing supplies etc.
Response	The Response phase is a reaction to the occurrence of an emergency. It occurs during and in the immediate aftermath of the event and includes actions taken to save lives and prevent further damage. Response is the coordination and management of resources (including personnel, equipment, and supplies) and putting preparedness plans into action. Response activities include surging medical capabilities, conducting evacuations, conducting public health surveillance and clinical guidance, taking actions to protect oneself and family, etc.
Recovery	The Recovery phase begins immediately after the threat to human life has subsided. The goal is to restore normalcy and critical community functions to the affected areas. Recovery consists of activities such as providing basic necessities for affected populations in need, rebuilding damaged structures, reducing vulnerability to future emergencies, etc.
Mitigation and Community Resilience	Mitigation is the effort to reduce loss of life and property by lessening the impact of emergencies. It refers to the actions and activities that reduce the chance of an emergency happening and prevent or minimize their effects. Mitigation activities can and should be done before an emergency occurs, and they are also essential in the aftermath of every emergency. Examples of mitigation activities include creating HCCs and including partners in local planning efforts. Implementation of hazard mitigation factors leads to building stronger, safer, and smarter communities that are better able to reduce future injuries and future damage. Community resilience promotes strong community systems and achieving equity by eliminating disparities around SDOH.
Steady State	Steady state is the term used in emergency management to describe when conditions are not being impacted by an emergency. Planning and mitigation activities take place during steady state.

Appendix B: Healthy People 2030 SDOH Objectives

There are several Healthy People 2030 objectives that relate to CYSHCN and their families/caregivers. Below is a sample of those objectives:

SDOH Objective	Category
Increase the proportion of eligible students participating in the Summer Food Service Program	AH-R03
Increase the proportion of parents and guardians who know the emergency or evacuation plan for their children's school	PREP-D01
Increase the proportion of children and adolescents who receive care in a medical home	MICH-19
Reduce the rate of deaths in children and adolescents aged 1 to 19 years	MICH-03
Increase the proportion of children and adolescents with special health care needs who have a system of care	MICH-20
Increase the proportion of children who receive a developmental screening	MICH-17
Increase the proportion of children aged 3 to 5 years who get vision screening	V-01
Increase the proportion of children who are developmentally ready for school	EMC-D01
Increase the proportion of children with developmental delays who get intervention services by age 4 years	EMC-R01
Increase the proportion of children and adolescents with communication disorders who have seen a specialist in the past year	HOSCD-05
Increase the proportion of children who participate in high-quality early childhood education programs	EMC-D03
Increase the proportion of schools with policies and practices that promote health and safety	EH-D01
Increase the proportion of students participating in the School Breakfast Program	AH-04
Increase the proportion of students with disabilities who are usually in regular education programs	DH-05
Increase the proportion of high school students who graduate in 4 years	AH-08
Increase the proportion of public schools with a counselor, social worker, and psychologist	AH-R09
Increase the proportion of children and adolescents who communicate positively with their parents	EMC-01
Increase the proportion of children and adolescents who show resilience to challenges and stress	EMC-D07
Increase the proportion of trauma-informed early childcare settings and elementary and secondary schools	AH-D01
Increase the proportion of children and adolescents with symptoms of trauma who get treatment	AH-D02
Reduce the proportion of public schools with a serious violent incident	AH-D03
Reduce the number of young adults who report 3 or more adverse childhood experiences	IVP-D03

Appendix C: Relevant Legislation and Regulations

Federal law mandates that in the event of a public health emergency, the health and medical needs and considerations of at-risk individuals are considered. Applicable laws, executive orders, and policies that may impact emergency planning and response for CYSHCN issued at the federal level can be found below.

Legislation Type	Examples
Federal Laws	<ul style="list-style-type: none"> • Federal laws prohibit discrimination and mandate the inclusion of certain at-risk individuals. These laws are a primary vehicle for many CYSHCN to receive services and/or accommodations. Under Federal anti-discrimination laws, “protected classes” include various groups, including but not limited to age, race, color, national origin, religious beliefs, gender, and disability. <ul style="list-style-type: none"> ▪ Section 504 of the Rehabilitation Act, which prohibits discrimination of individuals based on disability in terms of employment, access to services, and use of other programs that receive federal financial assistance. This includes federally funded emergency shelters. ▪ Americans with Disabilities Act, which prohibits discrimination against individuals with disabilities in employment, transportation, and access to state and local government services. ▪ Individuals with Disabilities Education Act (IDEA), which makes free public education as well as special education services free to children with disabilities. • Social Security Act (SSA): Through section 1135 of the Social Security Act, the HHS Secretary can temporarily modify or waive certain Medicare, Medicaid, Children’s Health Insurance Program (CHIP), and Health Insurance Portability and Accountability Act (HIPAA) requirements when he declares public health emergency and the President has declared an emergency or major disaster under the Stafford Act or National Emergencies Act. • The Public Health Service (PHS) Act (Public Law 117-204, as amended) is a federal law that forms the foundation of HHS’ legal authority for responding to public health emergencies and provides authority for many ASPR programs and activities. Relevant amendments to the PHS Act include the Pandemic and All-Hazards Preparedness Act of 2006 (PAHPA), which established ASPR, the Pandemic and All-Hazards Preparedness Reauthorization Act of 2013 (PAHPRA), and the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 (PAHPAIA). Among other items, PHS Act: <ul style="list-style-type: none"> ▪ Requires HHS to develop The National Health Security Strategy and implementation plan for public health emergency preparedness and response, taking into account the health and medical needs of at-risk individuals. The National Health Security Strategy identifies potential health emergency threats and defines goals to implement and protect against them. ▪ Authorizes the HHS Secretary to appoint a Director of At-Risk Individuals to oversee development and implementation of emergency preparedness goals with respect to the needs of at-risk individuals. ▪ Authorizes various public health and medical preparedness programs, including the ASPR Hospital Preparedness Program (HPP) and CDC Public Health Emergency Preparedness (PHEP) cooperative agreements. • The Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) establishes the statutory authority for most federal disaster response activities and assistance to state, local, and tribal governments for disasters and emergencies covered by the Act. In particular, the Stafford Act creates the primary system for federal financial and physical assistance when the President declares an emergency or major disaster under the Act. • As required under the Kids in Disasters Well-being, Safety, and Health Act of 2007, the National Commission on Children and Disasters was established by Congress and the President to identify gaps in disaster preparedness, response, and recovery for children and to make recommendations to close the gaps. The Commission’s final report includes recommendations related to child physical and mental health, traumatic exposure, housing, transportation, evacuation, emergency

Legislation Type	Examples
	<p>management, and specific needs related to child-serving settings, such as schools, juvenile justice, and child welfare.</p>
<p>Federal Policy Strategies</p>	<ul style="list-style-type: none"> • The 2022 National Strategy to Support Family Caregivers supports family caregivers of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them. Developed by advisory councils created by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act. • The National Health Security Strategy, discussed above, establishes a framework for strengthening the national capability to prevent, detect, assess, prepare for, mitigate, respond to, and recover from disasters and emergencies. The strategy describes how the U.S. can improve readiness and adapt operational capabilities to address ever-changing health security threats.
<p>Executive Orders</p>	<p>The following Executive Orders highlight the important of incorporating health equity and/or climate change resilience into all facets of public health.</p> <ul style="list-style-type: none"> • Summary of Executive Order 13045 - Protection of Children From Environmental Health Risks and Safety Risks, which prioritizes efforts across agencies on identifying and addressing environmental health risks and safety risks that disproportionately impact the health of children.

Appendix D: Populations and Settings

This toolkit references various populations and settings of interest, considering where people live, work, and learn. This is based on, but is not limited to, the following populations and settings, as referenced in the [Presidential COVID-19 Health Equity Task Force Final Report and Recommendations](#). Many population groups have intersectional characteristics; for example, a high proportion of runaway and CYSHCN experiencing homelessness may also identify as LGBTQIA+.

Racial/Ethnic Groups

- American Indian/Alaska Native American Indian/Alaskan Native (AI/NI)
- Asian/Asian American, Native Hawaiians and Pacific Islanders
- Black/African American
- Hispanic/Latino

Groups Likely to Face Barriers, Have Disproportionately Fewer Resources, or Otherwise More Likely to be Medically Underserved

- Immigrants/refugees/asylees
- LGBTQIA+ people
- People with low income
- People experiencing homelessness
- Veterans or military personnel and their families/caregivers
- Women and girls
- People with disabilities
- People with chronic medical conditions
- People with behavioral health conditions, including substance use disorder and mental health conditions
- People with long-term mental illness or long-term psychiatric disability
- People who require long-term services and supports
- People who are uninsured or underinsured

Special Age Population

- Children (younger than 12)
- Youth (12–17)
- Young adults (18–25)
- Older adults (65 and older)

Workers

- Agricultural industry workers (includes migrant workers and meat packing/food processing industry)
- Essential workers
- Frontline workers

Geographic Areas

- Rural
- Remote
- Tribal
- Territorial

Congregate Settings

- Carceral settings (i.e., jails, prisons, detention centers)
- Homeless shelters (includes heating and cooling centers)
- Long-term care facilities (e.g., nursing homes, skilled nursing facilities)
- Shared housing (e.g., group homes, assisted living, dormitories)
- Congregate Worship Centers

Other Relevant Settings

- Business
- Childcare facilities (e.g., Head Start, Early Head Start, in-home daycare)
- Health care facilities/ambulatory care
- Schools (early childhood, K-12, and post-secondary educational institutions)
- Transportation (e.g., public transportation, private transportation, gig transportation, accessible/paratransit, EMS, air travel, trains)

Appendix E: Data Sources and Analysis Tools for Emergency Planning for CYSHCN and Their Families/Caregivers

Providers can use the included data sources and analysis tools to better understand the demographics and makeup of their community, the threats and hazards that are more likely to occur, and what can be done to equitably reduce the personal risks and impacts of those hazards. These resources can be used to support equity across the emergency management cycle.

Data Source or Analysis Tool	Description
CDC/ATSDR's Geospatial Research, Analysis & Services Program (GRASP)	Creates maps using U.S. Census tracts to help emergency planners and public health officials identify communities that will most likely need support before, during, and after a hazardous event. The CDC/ATSDR SVI ranks each tract on 15 variables, including poverty, lack of vehicle access, and crowded housing.
Census Opportunity Atlas on Child Outcomes	Includes tract-level data of children's outcomes in adulthood covering nearly the entire U.S. population. The data allows researchers to trace roots of these outcomes back to SDOH in the regions where adults grew up as children. Indicators include income distribution, employment, demographics (race, sex, age), and birth rates.
Census Response Outreach Area Mapper	Provides a socioeconomic and demographic characteristic profile of hard-to-survey communities across the U.S., which helps users devise a tailored outreach plan based on ethnicity, language, age, and other demographics.
Census Bureau Data	National and state demographic and economic data, displayed in tables, graphs, and maps. There are several datasets available, including the 2020 Census, the American Community Survey, and the American Housing Survey. This data supports health care, public health, and social services providers in understanding who lives in their community, such as number of children and youth, race and ethnicity, common languages spoken at home, and housing status.
Census Bureau's Community Resilience Estimates (CRE) Program	Provides publicly available data on the extent to which neighborhoods in the U.S. are at-risk for public health emergencies and natural disasters. This data is intended to assist emergency planners and community organizers to prepare their communities for such events – however, it can also inform health care, public health, and social services providers about the risks of their own communities.
Climate-related Risk Analysis Tools	Data tools, which can be filtered by topic and/or tool functionality, to help manage climate-related risks and opportunities and help build resilience to extreme events.
CRE for Equity	Launched in January 2022, includes a dataset and dashboard measuring various indicators of equity and social vulnerability in communities across the U.S. These indicators include factors beyond health-related indicators, such as Internet access. When combined with general demographic data from the Census, CRE for Equity can help health care, public health, and social services providers and emergency planners understand how their communities would be affected by emergencies as well as what resources they need for preparedness efforts. For more, see Census equity data tools .
Department of Education Data and Statistics	Includes several data sources, such as the National Center for Education Statistics , and data stories, such as Our Nation's English Learners , that provide key demographic and education-related data on children and youth.
HHS emPOWER Program	The HHS emPOWER Program provides federal data, mapping, and artificial intelligence tools, as well as training and resources, to help communities nationwide protect the health of Medicare beneficiaries at-risk during an emergency. In addition, ASPR provides states and territories, who volunteer to participate, with guidance, technical assistance, and tools to develop and generate complementary emPOWER datasets of at-risk children and other adults in their state/territory-operated Medicaid and CHIP programs.
Environmental Justice (EJ) Screen	An environmental justice mapping and screening tool that provides EPA with a nationally consistent dataset and approach for combining environmental and

Data Source or Analysis Tool	Description
	demographic indicators. EJScreen users choose a geographic area; the tool then provides demographic and environmental information for that area.
Federal Interagency Forum on Child and Family Statistics	A network of 23 Federal government agencies involved in research and activities related to children and families. The Forum recently published a 2021 Report on Key National Indicators of Well-Being of children , which includes statistics and trends over time on indicators in seven domains: family and social environment, economic circumstances, health care, physical environment and safety, behavior, education, and health.
Local Data Sources	Integrated health systems, state and local governments, and pediatric practices may have specific data on the CYSHCN and their peers in their community, such as Medicaid claims data or local registries. For example, the Oregon Emergency Medical Systems for Children (EMS-C) Registry for CYSHCN pilot is funded by the Title V MCH Services Block Grant.
National EMS Information System (NEMSIS)	NEMSIS provides the framework for collecting, storing, and sharing standardized EMS data from States nationwide. The NEMSIS uniform dataset and database help local, State, and national EMS stakeholders more accurately assess EMS needs and performance, as well as support better strategic planning for the EMS systems of tomorrow.
National Survey of Children’s Health (NSCH) and the Data Resource Center for Child and Adolescent Health	An online data repository that includes data and statistics on various indicators of child health in the U.S., and an online data center that provides user-friendly information about, data findings on, and datasets and codebooks for the NSCH.
Pediatric Readiness Assessment	The National pediatric Readiness Assessment is intended to be used to evaluate overall pediatric readiness in Emergency Departments. It is based on guidelines developed in the 2018 Policy Statement: Pediatric Readiness in the Emergency Department .
Title V MCH Services Block Grant Program	A program, administered by HRSA, that provides information by state on the number of children and other stakeholders served by Title V programs, as well as their annual funding. This includes community-specific information that can help health care, public health, and social services providers understand common challenges faced by the families/caregivers they serve, as well as resources or services they use most often.

Appendix F: Emergency Plans

To aid in shared decision-making for emergency planning, providers may consider talking through the following sample questions, aligned to the [CMIST Framework](#), with CYSHCN and their families/caregivers as they develop an emergency plan.¹⁰¹

- **Communication:** How will I receive emergency alerts and warnings in my preferred format and language (e.g., TV, radio, text message)? How will this change if wi-fi or cell services are disrupted?
- **Maintaining Health:** What will I do if water service, heat, or air conditioning is disrupted for one or more days? What is my shelter plan (e.g., remain indoors, shelter in home, move to emergency shelter)? Do I have all necessary supplies, equipment, and medication? How will I refill prescriptions if local pharmacies are not available or accessible? How will I continue primary health care and behavioral health visits?
- **Independence:** How will I continue to use DME and devices that require electricity if the power goes out? Do I have a safe back-up power supply and how long will it last? Do I have the assistive devices I would need in my home or in an alternate location (e.g., communication aids, vision aids)? How will I care for my service animal/pet during and after an emergency?
- **Support and Safety:** How will I get required personal care assistance if my caregiver cannot reach me? Where will I meet my family or caregiver if we get separated or if the emergency happens during work and/or school? If I need to go to a temporary care setting, can my caregiver remain or access it frequently?
- **Transportation:** What is my evacuation plan, including accessible transportation needs? What transportation services do I need for medical appointments, non-medical appoints, and errands (e.g., groceries)?¹⁰²

¹⁰¹ FEMA. [Preparing for Disaster for People with Disabilities and other Special Needs](#).

¹⁰² Department of Transportation, Federal Highway Administration. [Evacuating Populations with Special Needs](#).

Appendix G: Example Organizations, Programs, and Services

The following is a sampling of different types of CBOs with whom providers can establish working relationships to enable greater information exchange and collaboration in the event of an emergency.

Category	Name	Description
Family-Led Organization	The Center for Parent Information and Resources (CPIR)	The CPIR provides family-friendly information and direct support to parents of CYSHCN and serves as a resource-sharing forum for Parent Centers. Parent Centers are hubs that provide various direct services to CYSHCN, their families, and professionals who serve them.
Family-Led Organization	Emergency Management Services for Children (EMSC), Family Advisory Network	EMSC created the Family Advisory Network (FAN) to facilitate the inclusion of family representatives in state EMSC programs. FAN members contribute to their state program activities in numerous ways, including, but not limited to serving as members, chairs, and co-chairs of their state EMSC advisory committee; coordinating special community outreach projects; assisting with the development and implementation of EMSC policy objectives; and helping to plan, present, and promote educational offerings within their state.
Family-Led Organization	Family-to-Family Health Information Centers (State/Territory F2F)	F2F HICs are hubs that provide critical support to families caring for CYSHCN and are located in all fifty states, in five U.S. territories, the District of Columbia, and three tribal communities
Family-Led Organization	Family Voices Affiliate Organizations (FVAO)	FVAOs are SLTT nonprofits led by family members of CYSHCN that work to advance the collective effort to keep families/caregivers at the center of children’s health care. FVAOs exist in most states and in many cases, the FVAO is the same organization that serves as the Family-to-Family Health Information Center (F2F) in that state.
Youth-Focused Organization	FEMA Corps	FEMA Corps is a team-based program that gives 18 to 24-year-old participants the opportunity to travel around the U.S. and serve communities impacted by disaster. Participants gain training and experience while providing important support to disaster survivors and communities.
Youth-Focused Organization	FEMA’s Teen Community Emergency Response Team (CERT) Program	FEMA’s Teen CERT Program is a national program of volunteers trained in disaster preparedness and emergency response. Youth volunteers are trained in disaster preparedness and emergency response and lead a variety of community-based activities such as organizing volunteers, assisting survivors, providing damage assessment information and more.
Youth-Focused Organization	FEMA’s Youth Preparedness Council	Every year, FEMA gathers youth leaders interested in disaster preparedness and provides opportunities to participate in disaster preparedness projects nationally and locally. The council also serves as a platform for adolescents to present their perspectives, feedback, and opinions to FEMA staff, culminating in the annual Youth Preparedness Council virtual summit.
Youth-Focused Organization	HOSA-Future Health Professionals	HOSA supports students’ career development in the health professions, serving over 165,000 students across 3,000 chapters in the U.S.

Category	Name	Description
Family-Led Organization	National Federation of Families/caregivers for Children’s Mental Health (FFCMH)	The FFCMH adopts person- and family-centered care in advocating for the rights of families/caregivers with children with mental, emotional, and behavioral needs. They achieve this by developing policies, collaborating with other family-run organizations, and providing support and resources to families/caregivers of children with mental health/substance use challenges.
Family-Led Organization	Parent to Parent (P2P) USA	P2P is a program that helps families/caregivers with CYSHCN access one-on-one emotional support. P2P USA encompasses a broader, nationwide network of various P2P programs in all 50 U.S. states that are helping families/caregivers connect with trained support parents.
Youth-Focused Organization	Public Health AmeriCorps	AmeriCorps and the CDC have launched Public Health AmeriCorps to recruit, train, and develop of the next generation of public health leaders who will be ready to respond to the nation’s public health needs. The program has two goals: address public health needs of local communities by providing support in state and local public health settings and advancing more equitable health outcomes for underserved communities; and create pathways to good quality public health-related careers through onsite experience and training, with a focus on recruiting AmeriCorps members who reflect the communities in which they will serve.
Youth-Focused Organization	Youth Conservation Corps	The United States Youth Conservation Corps (YCC) is a summer youth employment program that engages young people in meaningful work experiences at national parks, forests, wildlife refuges, and fish hatcheries while developing an ethic of environmental stewardship and civic responsibility. YCC programs are generally 8 to 10 weeks and members are paid the minimum wage for a 40-hour work week. YCC opportunities provide paid daytime work activities with members who commute to the Federal unit daily.
Youth-Focused Organization	Voices of Youth	Voices of Youth is UNICEF’s global digital community for young people to learn about development issues (e.g., environment, rights of people with disabilities) and to express their opinions. Voices of Youth seeks to create a space that will help young people develop into active global citizens equipped to communicate and collaborate effectively to make a positive difference in their countries and communities.
Federal-SLTT Benefits Programs	Children’s Health Insurance Program (CHIP)	Provides health coverage to eligible children, through both Medicaid and separate CHIP programs. CHIP is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
Federal-SLTT Benefits Programs	Medicaid	Provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, older adults, and people with disabilities. Medicaid is administered by states, according to federal requirements.
Federal-SLTT Benefits Programs	National School Lunch Program (NSLP)	Provides nutritionally balanced, low-cost, or free lunches to children each school day. NSLP is a federally assisted meal program operating in public and nonprofit private schools and residential childcare institutions.
Federal-SLTT Benefits Programs	Supplemental Nutrition Assistance Program (SNAP)	Provides nutrition benefits to supplement the food budget of needy families/caregivers so they can purchase healthy food and move towards self-sufficiency

Category	Name	Description
Federal-SLTT Benefits Programs	Temporary Assistance for Needy Families (TANF)	Provides states and territories with flexibility in operating programs designed to help low-income families/caregivers with children achieve economic self-sufficiency. States use TANF to fund monthly cash assistance payments to low-income families/caregivers with children, as well as a wide range of services.
Nonprofit, Advocacy, and Professional Organizations	American Academy of Family Physicians (AAFP)	AAFP promotes the practice of family medicine by advocating on behalf of family physicians on various topics, including health care coverage, delivery, technology, and public health. Physicians in AAFP state chapters have connections to state and local governments, as well as insights on health care resources and considerations for family health.
Nonprofit, Advocacy, and Professional Organizations	American Academy of Pediatrics (AAP)	AAP provides a forum for pediatricians to improve the physical, mental, and social health of infants, children, and adolescents. AAP has state chapters that offer an array of events, research, and expertise about child health in their specific regions that can better inform local emergency planning. In addition, AAP provides several online resources and guidance about emergency planning for CYSHCN.
Nonprofit, Advocacy, and Professional Organizations	American Red Cross	The American Red Cross provides emergency response and assistance for over 60,000 small- and large-scale disasters every year. Their staff have invaluable on-the-ground experience providing relief in the form of financial assistance, community-based recovery, safe shelters, clean water, and medical equipment.
Nonprofit, Advocacy, and Professional Organizations	American College of Emergency Physicians (ACEP)	Representing more than 38,000 emergency physicians, emergency medicine residents and medical students, ACEP promotes the highest quality of emergency care and is the leading advocate for emergency physicians.
Nonprofit, Advocacy, and Professional Organizations	Association of Maternal & Child Health Programs (AMCHP)	AMCHP is a national resource, partner, and advocate for state public health leaders who work and support state maternal and child health programs, and others working to improve the health of women, infants, children, youth, parents, families, and communities.
Nonprofit, Advocacy, and Professional Organizations	Association of State and Territorial Health Officials (ASTHO)	ASTHO is a nonprofit organization committed to supporting the work of state and territorial public health officials and furthering the development and excellence of public health policy nationwide. ASTHO's membership is comprised of 59 chief health officials from each of the 50 states, Washington, D.C., five U.S. territories, and three Freely Associated States. ASTHO also supports peer communities of state and territorial health leaders and senior executives in health departments who work with the over 100,000 public health professionals employed at state and territorial public health agencies.
Nonprofit, Advocacy, and Professional Organizations	Center for Positive Behavioral Interventions and Supports (PBIS)	Funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) and the Office of Elementary and Secondary Education (OESE), the Center on PBIS supports schools, districts, and states to build systems capacity for implementing a multi-tiered approach to social, emotional and behavior support. The broad purpose of PBIS is to improve the effectiveness, efficiency, and equity of schools and other agencies. PBIS improves social, emotional, and academic outcomes for all students, including students with disabilities and students from underrepresented groups.

Category	Name	Description
Nonprofit, Advocacy, and Professional Organizations	Children’s Hospital Association (CHA)	CHA is a national network of children’s hospitals that aims to advance child health through innovation in the quality, cost, and delivery of care.
Nonprofit, Advocacy, and Professional Organizations	Emergency Nurses Association (ENA)	ENA serves as a global community for emergency nurses that aims to advance excellence, policy advocacy, and education in emergency nursing.
Nonprofit, Advocacy, and Professional Organizations	Association of State and Tribal Home Visiting Initiatives (ASTHVI)	ASTHVI is a nonprofit, nonpartisan collaboration of state and Tribal administrators of home visiting programs. ASTHVI is dedicated to the effective implementation and improvement of home visiting programs at the state, territory, and Tribal level in order to improve the lives of families/caregivers and young children.
Nonprofit, Advocacy, and Professional Organizations	National Alliance on Mental Illness (NAMI)	NAMI is the National Alliance on Mental Illness, the nation’s largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.
Nonprofit, Advocacy, and Professional Organizations	National Association of County and City Health Officials (NACCHO)	NACCHO comprises nearly 3,000 local health departments across the U.S. that form an organization focused on being a leader, partner, catalyst, and voice for change for local health departments around the nation.
Nonprofit, Advocacy, and Professional Organizations	National Child Traumatic Stress Network (NCTSN)	NCTSN was created to raise the standard of care and increase access to services for children and families/caregivers who experience or witness traumatic events.
Nonprofit, Advocacy, and Professional Organizations	Save the Children	Save the Children drives global and local efforts ensuring children can reach their full potential in health and education. In the U.S., Save the Children leads hundreds of projects in communities impacted most by inequality, including emergency response efforts, providing them with on-the-ground expertise.
Nonprofit, Advocacy, and Professional Organizations	School-Based Health Alliance	The School-Based Health Alliance is a national nonprofit promoting school-based health care to achieve health equity among children and students. They conduct research and advocates for policies to fund and support School-Based Health Centers (SBHCs) , which are partnerships between schools and community health organizations that provide health care and preventive services directly to children.
Nonprofit, Advocacy,	Society for Adolescent Health	SAHM is a multidisciplinary organization committed to improving the physical and psychosocial health and well-being of all adolescents through advocacy, clinical

Category	Name	Description
and Professional Organizations	and Medicine (SAHM)	care, health promotion, health service delivery, professional development, and research.
Nonprofit, Advocacy, and Professional Organizations	Unity™ Consortium	Unity™ Consortium provides action-oriented leadership, innovation, and education on preventive health and immunization for adolescents and young adults.
Nonprofit, Advocacy and Professional Organizations	Administration for Community Living (ACL) Disability Programs	The aging and disability networks are made up of local, state, and national organizations and committed advocates working to support older adults and people with disabilities. Some organizations focus on a particular type of disability, age group, or type of service, whereas others have a more comprehensive mission.

Appendix H: Potential Agreements

Providers may consider establishing formal agreements with partners. These agreements may be used to facilitate data and resource sharing and to identify roles and responsibilities during an emergency. The following types of agreements are typically used across the emergency management cycle.

- **Memoranda of Understanding (MOUs):** Established to document agreements to collaborate, communicate, respond, and support one another before, during, or after an emergency.
- **Mutual Aid Agreements (MAA):** An agreement between or among two or more parties that address the processes and policies in place for requesting and sharing staff, equipment, and consumable resources, as well as payment for services or material provided.
- **Emergency-Specific MOUs:** An agreement used by federal, state, local, tribal, or territorial agencies to define relationships and increase communication, collaboration, and transparency among agencies and organizations in the event of an emergency. The emergency-specific MOU should be customized to reflect the resources devoted by all parties, as well as each party's emergency-specific needs, to address the specific circumstances that parties may face while coordinating response and recovery efforts.¹⁰³

¹⁰³ ASPR. [Capacity-Building Toolkit for including Aging & Disability Networks in Emergency Planning.](#)

Appendix I: Emergency Shelters

Emergency shelters are typically able to accommodate a large number of individuals while also providing space and equipment that help them maintain their well-being in the short-term. To support CYSHCN and their families/caregivers, providers may advise on sheltering considerations as well as help CYSHCN and their families/caregivers identify the most appropriate shelter. Considerations include:^{104, 105}

- **Shelter Staff:** Require background checks for shelter personnel.
- **Supervision:** Ensure adequate supervision for CYSHCN separated from families/caregivers.
- **Human Trafficking and Abuse:** Train personnel to identify signs of human trafficking and abuse:
 - Review [CDC resources for Shelter Personnel on Human Trafficking in the Wake of a Disaster](#).
 - Know the National Human Trafficking Hotline (888-373-7888 or text “HELP” to 233733).
 - Report suspected child exploitation to the National Center for Missing & Exploited Children, at 800-THE-LOST.
- **Quarantine and Isolation:** Arrange for quarantine or isolation spaces for people who are ill, within a shelter or in a separate location (e.g., hotels, dormitories) ([FEMA’s Mass Care Planning Considerations](#)).
- **Power Availability:** Provide access to sources of power (e.g., outlets, batteries) for CYSHCN who rely on electricity-dependent DME or devices (e.g., oxygen) and for the charging of mobile phones, tablets, and laptops. During the Texas blizzard and power outage in 2021, many families/caregivers initially focused on gaining access to a power source.
- **Backup Medical Supplies and Assistive Equipment:** Procure first aid kits as well as common forms of DME, such as wheelchairs and crutches, that are designed for CYSHCN, as families/caregivers may not be able to evacuate with all equipment.¹⁰⁶
- **Safe Sleeping Spaces and Equipment:** Offer safe and quiet places to sleep and necessary sleep-related items to accommodate CYSHCN who must sleep on specific types of beds or mats.
- **Quiet Areas:** Create low-stimulation and low-noise zones that can relieve stress for CYSHCN and their families/caregivers – particularly CYSHCN with developmental disabilities (such as those with an autism diagnosis) that benefit from reduced external stimuli. These can be separate rooms in the same building.
- **Food and Drinks:** Stock non-perishable food items (e.g., canned food) and beverages, with the most essential option being water. Food and drinks may also include items tailored towards dietary restrictions or other nutritional needs of CYSHCN and their families/caregivers (e.g., soft, or blended foods, special formulas, vegetarian items). Additionally, the shelter should include a safe space to store special dietary foods.
- **Basic Supplies:** Provide blankets, extra clothing, basic sanitary items (e.g., soap, hand sanitizer, tissues), as well as menstrual products (with awareness of cultural and religious beliefs surrounding menstruation).
- **Toys and Sensory Kits:** Stock supplies that can support CYSHCN with regulating external stimuli during emergencies, such as noise cancelling headphones and visual or tactile toys.
- **Recreational Spaces and Supplies:** Create indoor and outdoor (if possible) spaces for recreation and entertainment, such as physical exercise, video games, and reading, that can relieve stress.
- **Language Access and Effective Communication Support:** Current civil rights guidance during emergencies, in reference to Section 504 of the Rehabilitation Act and the Civil Rights Act of 1964, prohibits any federally funded program (including emergency shelters receiving federal funds) from

¹⁰⁴ American Red Cross. [Sheltering Handbook Disaster Services](#).

¹⁰⁵ [ADA Best Practices Tool Kit for State and Local Governments](#). Chapter 7 Addendum 2: The ADA and Emergency Shelters: Access for All in Emergencies and Disasters.

¹⁰⁶ FEMA. [Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters](#).

discriminating against individuals based on disability.^{107,108} Shelter staff should include individuals who are representative of the community and trained in translation and interpretation services to support cultural and linguistic competency. Other forms of communication support include auxiliary aids such as large print materials, braille print materials, assistive listening devices, hearing aid compatible phones and more.

- **Cultural Appropriateness.** Emergency shelter planning should take into consideration the community's population and their specific need (e.g., dietary requirements, religious requirements, etc.).
- **Delivery of Health Care and Social Services:** Emergency shelters often serve as a location for urgent and basic health care services, in addition to essential social services (e.g., nutrition support, behavioral health referrals). For example, the American Red Cross trains volunteers to assess client needs for referral using the CMIST Framework to address access and functional needs in emergency shelters.¹⁰⁹ This includes providing health care services, equipment, and medication such as wound management supplies, anxiety management tools, backup medicine, and oxygen supplies. First responders and providers may serve as volunteer staff that provide these services to CYSHCN and their families/caregivers.

¹⁰⁷ FEMA. [FEMA Section 504 Implementation Plan](#).

¹⁰⁸ U.S. Department of Justice. [Guidance to State and Local Governments and Other Federally Assisted Recipients Engaged in Emergency Preparedness, Response, Mitigation, and Recovery Activities on Compliance with Title VI of the Civil Rights Act of 1964](#).

¹⁰⁹ American Red Cross. [CMIST Worksheet](#).

Appendix J: Continuity of Operations Planning

Continuity of operations planning (COOP) will help providers and their partners sustain services during an emergency. Providers may consider the following when planning for continuity:

- **Incident Command System (ICS):** Providers may consider establishing a chain of command and procedures or integrating into an established ICS to facilitate smooth coordination. As part of the National Incident Management System (NIMS) established by FEMA, the ICS establishes a hierarchy of positions involved in emergency management, specifying each role's actions and line of communication. This can help organizations create a chain of command among its staff, assigning them to different areas, getting updates, and requesting backup assistance when needed. Organizations can also create an ICS among a set of partners so they can coordinate response services, understand who to communicate with in each organization, and identify lines of authority and shared decision-making. For more information on the ICS, review [Appendix K](#).
- **Equipment and Supplies:** Organizations should plan for, via vendor contracts, and potentially purchase equipment and supplies that may be needed to support CYSHCN and their families/caregivers. For example, backup generators (e.g., purchased, leased, or borrowed), quick-connect adaptors, and extra batteries may be required to ensure access to electricity for populations that rely on power to operate electricity-dependent DME. Continuity planning should also include creating backup plans when shortages or delays occur. CYSHCN and their families/caregivers may require medication, PPE, oxygen, special dietary foods, and supplies (e.g., feeding tubes), and other medical items. Providers can collaborate with local governments, emergency planners, and suppliers to establish an understanding of essential equipment and supplies and identify opportunities for supply chain flexibility and resilience. This may involve:
 - Bolstering the organizational or local government stockpile of certain medical supplies and equipment.
 - Initiating agreements with multiple local and/or non-local suppliers.
 - Establishing transportation procedures for vendors to quickly reach affected areas.
 - Determining procedures for being alerted about supply shortages, and how to communicate those shortages to affected patients/clients.
 - Devising protocols for accessing and distributing limited supplies.
- **Triage:** Providers may establish triage protocols prior to emergencies that can cause medical surge. This includes not only establishing criteria for severity of injury and priority of treatment, but also working with emergency planning partners described in [Module 1: Partnerships and Coordination](#) to determine other logistics (e.g., where to set up triage centers during emergencies and supplies needed). The importance of triage protocols also applies to behavioral health services. Providers work with behavioral health partners to learn about behavioral health triage systems prior to emergencies, such as Psychological First Aid, an evidence-informed approach to help children, youth, adults, and families/caregivers in the immediate aftermath of a disaster.¹¹⁰
- **Personnel:** A continuity plan should include staffing plans to ensure sustained delivery of essential function during various emergency scenarios.¹¹¹ In addition, it may be beneficial to develop protocols for deploying personnel at the state and local level with expertise supporting CYSHCN to assist the essential workforce when needed.
- **Facilities:** Providers can work with their partners to determine which facilities can be used by CYSHCN and families/caregivers who have a range of specific needs in an emergency.¹¹²

¹¹⁰ NCTSN. [About PFA](#).

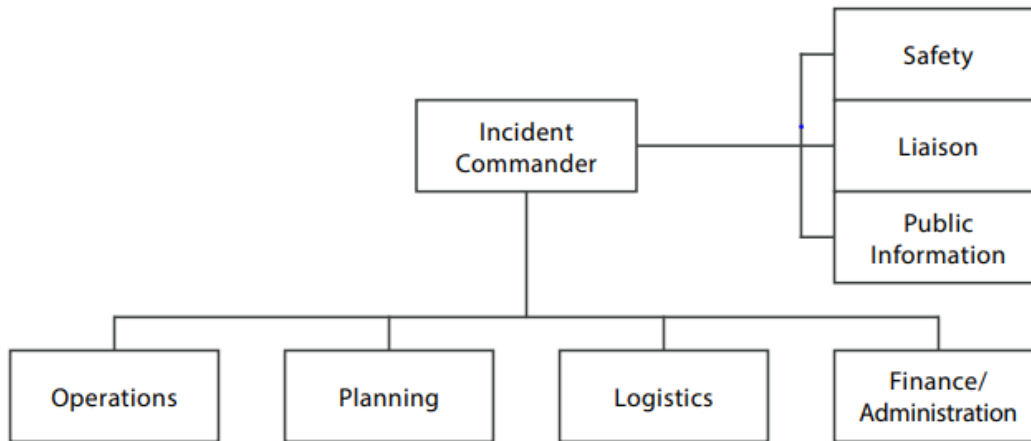
¹¹¹ FEMA. [Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters](#).

¹¹² CDC. [Disability and Health Inclusion Strategies](#).

Appendix K: Incident Command System (ICS)

An ICS is a standardized approach to the command, control, and coordination of emergency response that provides a common hierarchy within which responders from multiple agencies can be effective. The following information, in addition to more detail, can be found in [the Capacity-Building Toolkit for including Aging & Disability Networks in Emergency Planning](#) (pages 15-18).

An ICS structure may include an Incident Commander, Safety Officer, Liaison Officer, Public Information Officer, Operations Section, Planning Section, Logistics Section, and Finance/ Administration Section.



Each ICS position would have specific roles and responsibilities, such as the following positions that are likely to apply to a community organization:

ICS Position	Role/Responsibility
Incident Commander	Leads organization's on-scene response; establish incident objectives
Safety Officer	Ensure personnel safety; prepare safety plan; ensure safety messages are communicated; stop unsafe acts; correct unsafe conditions
Liaison Officer	Point of contact with outside agencies and companies; monitors operations to identify inter-organizational problems; facilitate inter-agency situational awareness
Public Information Officer	Develop information for use in media briefings; conduct periodic media briefings
Operations Section	Manage all tactical operations during the incident; ensure safe tactical operations for all responders
Planning Section	Conduct and facilitate planning meetings; assess current and potential impacts on people, property, environment
Logistics Section	Provides resources to stabilize the incident and support personnel, systems, and equipment
Finance/ Administration Section	Manages all financial aspects of the incident; provides financial and cost analysis information as requested

Appendix L: Relocation, Separation, and Reunification

In an emergency, there may be circumstances where CYSHCN and their families/caregivers need to temporarily relocate. When an emergency may necessitate temporary relocation, plans must be in place ahead of time to ensure they are discharged back to their home or original care setting and not inadvertently placed in a longer term care setting. Further, emergencies may also result in separation of CYSHCN from their families/caregivers, and while preventing the separation of children from their families/caregivers should be incorporated into emergency plans, reunification plans should be in place in the event of separation. To minimize separation, support separated CYSHCN, or facilitate reunification, providers may:

- Use a person- and family-centered care and shared decision-making model to identify supports needed, such as alternate caregivers or a temporary care setting.
- Work with schools to transport CYSHCN to nearby emergency shelters that have appropriate supervision for unaccompanied CYSHCN. These shelters can become a hub for family reunification.
- Collaborate with shelter staff to provide ID bracelets (such as bracelets of the same color, or other matching characteristics) to each member of a family to facilitate reunification.¹¹³
- Monitor the safety and health of unaccompanied CYSHCN and work with responders and emergency shelter staff to get them the care needed and equipment as they wait to be reunited with families/caregivers.
- Use the individual plans of care, especially specifications around emergency response and unification with families/caregivers.
- Coordinate with SLTT government agencies, law enforcement, schools, and emergency shelter staff to create procedures and facilitate reunification, including processes to identify children and youth who have been separated from their families, determine reunification locations, establish, and communicate locations for reunification, and identify staff who can assist these efforts.¹¹⁴ Reunification locations should consist of five areas:
 - **Check-In Area:** Where staff greet families/caregivers, or other emergency contacts of CYSHCN.
 - **Child Care Area:** Where staff oversee and care for children and youth. This area can also include options for keeping children entertained and distracted from the stressful situation.
 - **Release Area:** Where families/caregivers and emergency contacts complete administrative work to confirm they are the appropriate adults that should be reunified with their children.
 - **Command Area:** Where the staff leader or manager will oversee logistics of the reunification facility.
 - **Private Area:** Where staff can talk with families/caregivers privately to inform them if their child is missing, injured, or deceased.

¹¹³ Oklahoma State Department of Health. [Resource Guide for Access & Functional Needs of Children and Youth in Disaster Planning](#).

¹¹⁴ FEMA. [Post-Disaster Reunification of Children: A Nationwide Approach](#).

Appendix M: Building Resilience Against Climate Effects (BRACE) Framework

The BRACE Framework helps providers and their partners identify potential hazards and health outcomes, estimate disease burdens, and identify interventions that will help reduce the negative impacts of climate change on the health of CYSHCN and their families/caregivers.

1. **Anticipate Climate Impacts and Assess**

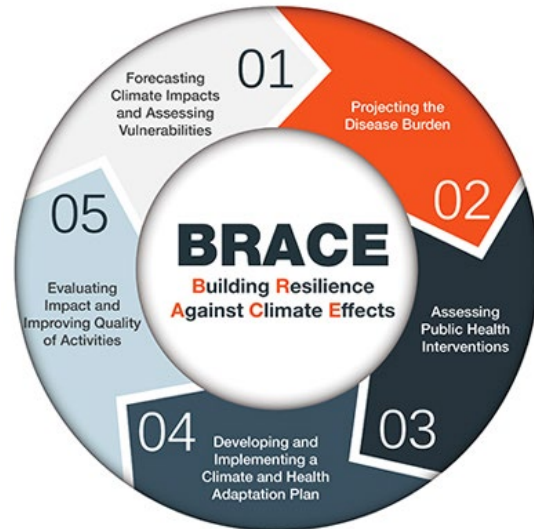
Vulnerabilities: Identify the scope of climate impacts, associated potential health outcomes, and populations (e.g., CYSHCN) and locations vulnerable to these health impacts

2. **Project the Disease Burden:** Estimate or quantify the additional burden of health outcomes associated with climate change (e.g., asthma, behavioral health challenges)

3. **Assess Public Health Interventions:** Identify the most suitable public health interventions for the identified health impacts of greatest concern

4. **Develop and Implement a Climate and Health Adaptation Plan:** Develop a written adaptation plan that is regularly updated. Disseminate and oversee implementation of the plan.

5. **Evaluate Impact and Improve Quality of Activities:** Evaluate the process and determine the value of information attained and activities undertaken



Appendix N: Language Access and Effective Communication During Response and Recovery

Emergency responders must be prepared to reach all members of the community during emergency response and recovery efforts, including individuals with access or functional needs. The following HHS [checklist](#) contains recommendations, action steps, and effective practices that can assist emergency responders.



DEPARTMENT OF HEALTH & HUMAN SERVICES

ENSURING LANGUAGE ACCESS AND EFFECTIVE COMMUNICATION DURING RESPONSE AND RECOVERY: A CHECKLIST FOR EMERGENCY RESPONDERS

As an emergency responder, it is critical for you to be prepared to effectively reach all members of the community during emergency response and recovery efforts. Survivors may include individuals with access and functional needs, such as persons with limited English proficiency (LEP) and persons with disabilities. Access to federally funded emergency response and recovery services must be provided to persons with LEP and persons with disabilities in accordance with federal civil rights laws, including Title VI of the Civil Rights Act of 1964 and Section 504 of the Rehabilitation Act of 1973.¹ These services may include providing language access services² to provide meaningful access and auxiliary aids and services to ensure effective communication.

<p>Who is a person with limited English proficiency (LEP)? A person who does not speak English as their primary language and who has a limited ability to read, write, speak, or understand English well.</p>	<p>Who is a person with a disability? A person who has a physical or mental impairment that substantially limits one or more major life activities. Note that persons with cognitive, vision, hearing, and speech impairments may have specific communication needs.</p>
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The following [recommendations](#), [action steps](#), and [effective practices for working with interpreters](#) can assist emergency responders in addressing the needs of persons with LEP and persons with disabilities regarding language access and effective communication:³

RECOMMENDATIONS	ACTION STEPS	✓
Supporting LEP Individuals and Persons with Disabilities		
Identify specific languages/dialects spoken by each major LEP and deaf/hard-of-hearing group in your area.	<ul style="list-style-type: none"> Access state and local demographic data, available through the U.S. Census Bureau, or interactive maps through the Department of Education. Identify public gathering spaces that serve persons with LEP, such as schools or local libraries that offer internet access or language access resources. Identify the type of Sign Language spoken in your area (i.e., American Sign Language, Spanish Sign Language, etc.). 	
Identify persons with disabilities who may need communication support, such as persons with vision, hearing, speech, or cognitive impairments.	<ul style="list-style-type: none"> Reach out to Centers for Independent Living (CILs), your state Developmental Disabilities Council, your state's Protection and Advocacy Agency, as well as organizations serving deaf/hard of hearing or blind/low vision populations. 	
Identify local partners that connect with and serve persons with LEP and persons with disabilities.	<ul style="list-style-type: none"> Reach out to hospitals and other health care facilities, community-based organizations, faith-based organizations, legal services. Connect with Refugee Resettlement and English as a Second Language programs. 	
Coordinate with media in TV, print, radio, and online platforms to share emergency information.	<ul style="list-style-type: none"> Prepare emergency messaging that is in plain language, short, culturally appropriate, in languages prevalent in the area, and in multiple formats, such as audio, large print, and captioning. See HHS' tips on using plain language. 	

¹ Other relevant federal laws, Executive Orders, and guidance that address the needs of persons with disabilities and/or persons with LEP include the Public Health Service Act, the Robert T. Stafford Disaster Relief and Emergency Assistance Act, the Post-Katrina Emergency Management Reform Act of 2006, Executive Orders 13166 and 13347, the National Response Framework, and the National Disaster Recovery Framework.

² There are two ways to provide language services: oral interpretation and written translation.

³ This guidance document is not a final agency action, does not legally bind persons or entities outside the Federal government, and may be rescinded or modified in the Department's discretion. Noncompliance with any voluntary standards (e.g., recommended practices) contained in this document will not, in itself, result in any enforcement action.

Appendix O: Acronyms

Acronym	Definition
AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
AI/AN	American Indian/Alaska Native
ACF	Administration for Children and Families
ADA	Americans with Disabilities Act
AFN	Access and Functional Needs
ASPR	Administration for Strategic Preparedness and Response
CDC	Centers for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CLAS	Culturally and Linguistically Appropriate Services
CMIST	Communication, Maintaining Health, Independence, Support and Safety, and Transportation
CMS	Centers for Medicare and Medicaid Services
COIN	Community Outreach Information Networks
COOP	Continuity of Operations Plan
DME	Durable Medical Equipment
EIIC	Emergency Medical Services for Children Innovation and Improvement Center
EMSC	Emergency Medical Services for Children
ESAR-VHP	Emergency System for Advance Registration of Volunteer Health Professionals
ESL	English as a Second Language
F2F	Family-to-Family Health Information Centers
FEMA	Federal Emergency Management Agency
HCC	Health Care Coalition
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
IHS	Indian Health Service
LEP	Limited English Proficiency
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual
LTRG	Long Term Recovery Group
MCH	Maternal-Child Health
MCHB	Maternal-Child Health Bureau
NCTSN	National Child Traumatic Stress Network
NHOPI	Asian, Native Hawaiian, and Other Pacific Islander

Acronym	Definition
OMH	Office of Minority Health
PPE	Personal Protective Equipment
PPN	Pediatric Pandemic Network
SAMHSA	Substance Abuse and Mental Health Services Administration
SNAP	Supplemental Nutrition Assistance Program
SDOH	Social Determinants of Health
USDA	United States Department of Agriculture
VOAD	Voluntary Organizations Active in Disasters

Appendix P: Glossary of Terms

Accessibility: Ensuring that all users of a product or service can access it regardless of the user's capabilities or AFN.

Access and Functional Needs: Irrespective of a specific diagnosis, status, or label, access and functional needs may interfere with a person's ability to access or receive medical care or limit a person's ability to act before, during, or after an emergency. Examples of individuals with access and functional needs include individuals with disabilities, who live in institutional settings, from diverse cultures, and who have LEP or are non-English speaking.

At-Risk Individuals: Individuals who may have additional needs before, during, or after an emergency in one or more of the following functional areas: communication, maintaining health, independence, support and safety, and transportation. At-risk individuals include children, older adults, individuals who are pregnant, and individuals who may need additional response assistance (e.g., individuals with chronic medical conditions, developmental disabilities/intellectual disabilities, limited mobility, mental health conditions, or substance use disorder).

Behavioral Health: The promotion of mental health, resilience, and well-being; the treatment of mental and substance use disorders; and the support of those who experience and/or are in recovery from these conditions, along with their families/caregivers and communities.¹¹⁵

Care Coordination or Case Managers: Care Coordination or Case Managers involves deliberately organizing patient care activities and sharing information among all providers involved to achieve safer and more effective care.

Children and Youth with Special Health Care Needs: Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally.

Children with Medical Complexity: A subset of CYSHCN characterized as children having family-identified service needs, severe chronic clinical conditions, functional limitations, and high utilization of health resources.

Climate Change: The capacity of an individual, community, or institution to understand potential climate impacts and respond dynamically and effectively to shifting climate circumstances and events.

CMIST Framework: A recommended approach for integrating the access and functional needs of at-risk individuals who may have additional needs that must be considered in planning for, responding to, and recovering from a disaster or public health emergency. CMIST is an acronym for the following five categories: Communication, Maintaining health, Independence, Support and Safety, and Transportation. The CMIST Framework provides a flexible, crosscutting approach for planning to address a broad set of common access and functional needs without having to define a specific diagnosis, status, or label.

Continuity of Operations: Guidance and plans for personnel, communications, and facilities in the event of an emergency. A Continuity of Operations Plan (COOP) builds resilience and mitigates effects of an emergency on an organization and the people it serves.

Cultural Competency: The ability of individuals and systems to respond respectfully and effectively to people of all cultures, classes, races, ethnic backgrounds, disability status, sexual orientations, and faiths

¹¹⁵ SAMHSA. [Behavioral Health Integration](#).

or religions in a manner that recognizes, affirms, and values the worth of individuals, families, tribes, and communities, and protects and preserves the dignity of each.

Disasters: Large-scale and cross geographic, political, and academic boundaries. Disasters require a level of response and recovery greater than local communities can provide.

Disaster Case Management: A time-limited process by which a skilled helper (disaster case manager) partners with a disaster-affected individual or family to achieve realistic recovery goals.¹¹⁶

Localized Emergencies: Small-scale, localized incidents which are resolved quickly using local resources (e.g., disruption in municipal services such as water, natural gas, roads, and transportation).

Emergency Management: The managerial function charged with creating the framework within which communities reduce vulnerability to hazards and cope with disasters and public health emergencies. Emergency management seeks to equip communities with the capacity to cope with hazards and disasters to promote and prioritize the safety of all, especially individuals most at-risk during an emergency.

Epidemic: Epidemic refers to an increase, often sudden, in the number of cases of a disease above what is normally expected in that population in that area

Equity: The consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.

Families/Caregivers: Adults responsible for the health, safety, and care of children and adolescents. Caregivers can include, but are not limited to, mothers, fathers, grandparents, relatives, legal guardians, and trusted childcare providers (e.g., early childhood educator, teacher).

Health Equity: Every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.

Human-Caused Disasters: Traumatic events that may cause loss of life and property (e.g., industrial accidents, shootings, acts of terrorism, incidents of mass violence).

Localized Emergencies: Emergencies within a localized geographic area resulting from the disruption in municipal services such as water, natural gas, roads, and transportation.

Mitigation: The effort to reduce loss of life and property by lessening the impact of disasters and emergencies. It refers to the actions and activities that reduce the chance of an emergency happening and prevent or minimize their effects. Mitigation activities can and should be done before an emergency occurs, and they are also essential after every emergency.

Natural Disasters: Large-scale geological or meteorological events (e.g., hurricanes, wildfires, floods) that have the potential to cause loss of life or property.

Outbreak: Carries the same definition of epidemic but is often used for a more limited geographic area.

¹¹⁶ National VOAD. [DCM Guidelines and Points of Consensus](#).

Pandemic: An epidemic that has spread over several countries or continents, usually affecting a large number of people.

Preparedness: Continuous dedication of time and resources, typically before an emergency strikes, for adequate planning, organizing, education, evaluation, and training, especially for events that cannot be mitigated.

Shared decision-making: Decision-making that empowers individuals to make health care decisions about their own well-being with provider guidance and support.

Social Determinants of Health: Conditions in the environment where people are born, live, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Systems of Care: An integrated, team-based network of providers that care for CYSHCN and their families/caregivers and promote coordinated, comprehensive, person- and family-centered systems of services.

Psychological First Aid: An evidence-informed approach that aims to reduce stress systems and assist in a healthy recovery following a traumatic event, natural disaster, public health emergency, or even a personal crisis.

Recovery: Beginning immediately after the threat to human life has subsided, this phase aims to restore normalcy and critical community functions to the affected areas.

Response: A reaction to the occurrence of an emergency. It occurs during and in the immediate aftermath of the event and includes actions taken to save lives and prevent further damage. Response is the coordination and management of resources (including personnel, equipment, and supplies) and putting preparedness plans into action.

Trauma: Results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.

Trauma-Informed Approach: A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization.