



**World Institute  
on Disability**



# Health Plan Member-Focused Emergency Practices Roadmap

It is “If and Not When”...No Health Plan Operates in a Disaster-Free Zone!

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This Roadmap is a work in progress and will evolve as new learning, continuous feedback, and new methods and tools become available. Therefore, you are encouraged to refine its content and provide the author ([jik@pacbell.net](mailto:jik@pacbell.net)) with feedback (See Appendix B. Feedback)



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## About the Author

This report was produced by [June Isaacson Kailes, Disability Policy Consultant](#). June's breadth and depth of experience in disability, accessibility, and functional needs issues are widely known. Respected as a writer, trainer, researcher, policy analyst, subject matter expert, and advocate, June's work focuses on building critical disability practice competencies and capabilities in health care and emergency management by using actionable details. These details operationalize the equity and specificity needed to include people with disabilities and others with access and functional needs. Much of her work converts the law, case laws, regulations, and guidance into tangible building blocks, tools, and operating procedures that close service gaps, prevent civil rights violations, and deliver inclusive, equally effective services.

## About the World Institute on Disability

The [World Institute on Disability \(WID\)](#) was established in 1983 as one of the first global disability rights organizations founded and continually led by people with disabilities. WID works to advance the rights and opportunities of over 1 billion people with disabilities worldwide, bringing research and policy into action and operationalizing inclusion. WID's work centers around digital tools for optimizing community living and employment; accessibility solutions; and excellence in disability inclusive emergency preparedness, disaster risk reduction, and climate resilience.



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## Executive Summary

The **purpose of this Roadmap** is to strengthen, create, promote, and embed emergency practices into member-centered health plans and processes which help members successfully deal with, live through, and survive emergencies. The project investigates and documents promising member-centered emergency interventions. These critical interventions include applying past lessons from COVID-19 and other co-occurring and previous emergencies.

During 2020 through 2021, a multipronged approach to information gathering included:

- 66 key informant interviews
- five organizational learning consultations with home health, health plans, and health plan companies
- review of online guidance content from government, researchers, and trade associations
- 26 subject matter experts, including 19 interviewees, reviewed and commented on the draft report

**Health plans are often overlooked** as essential partners before, during, and after emergencies. Yet, more than any other service system, health plans, public and private, serve most people with disabilities in the United States. In this document, health plans refer to health insurance plans across all lines of business, employer-sponsored coverage, individual and group insurance market, and public programs (Medicare and Medicaid).

Health plans play critical emergency roles in addressing and protecting their members' resilience, health, safety, and independence. In emergencies, health plans can prevent or mitigate the cascading of negative effects of typically well-controlled chronic health conditions. Like a house of cards, the usual balance can be disrupted or collapse easily. Targeted prevention includes protection from degradation or failure of:

- personal support systems
- loss of supplies





- loss of medications
- loss of technologies
- loss of customized accessible environments
- equitable access to disaster response programs, services, and activities

Much information exists on COVID-19 pandemic health plan innovation and promising practices. However, there is very little content on applying and retooling these practices for permanent and quick unpacking and deployment during future inevitable emergencies. Systems are needed to prevent loss of good practices and lessons and the need to be reinvented for the next emergency.

**The target audience** for this Roadmap is broad and addresses a range of stakeholder concerns, including providers, community-based organizations, and change agents, inclusive of:

- frontline health plan staff and leadership
- medical service providers, and home and community-based services
- provider organizations such as adult day programs, home health care services, and community-based agencies

These concerns include helping members before, during, and after emergencies. More specifically, the roles and possible actions of:

- accrediting organizations, standard-setting bodies, and quality assurance organizations
- disability-led, disability-focused, and community-based organizations
- emergency management consultants
- emergency managers and planners
- Federal and state legislatures
- Federal, state, and local health agencies
- grant makers
- health plan leadership and staff
- researchers

Anticipating those most receptive to its guidance and advice will include first adopter health plans that:

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- have strong “perceptions of threat” and operate from the “not if, but when” attitude about the risks of reoccurring disasters
- are in high hazard threat and disaster probability areas
- make natural connections with members who have the highest personal risk factors and experience disproportionate negative effects by service disruptions. For example, children, adults with disabilities, and older adults who need assistance in activities of daily living, use a variety of services and supports over an extended period and multiply marginalized individuals (poverty, non-English first language, Black, Indigenous, (and) People of Color, etc.
- offer comprehensive, coordinated care such as long-term services and supports helping members remain independent in their homes and communities through increased access to home and community-based services (HCBS), resulting in improved health and quality of life outcomes
- meet the clinical and non-clinical needs of high-cost, high-need managed care members through interdisciplinary, high-touch, and person-centered service
- are Medicare-Medicaid plans, Medicare Special Needs plans, managed care long-term services and supports plans and PACE (Program of All-inclusive Care for the Elderly)

**Embedding emergency practices and services** can lead to better member health, resiliency, and health cost savings, especially for high-risk and high-cost individuals who live with complex health care conditions.

These practices can prevent or reduce:

- use of ambulances
- emergency department visits
- hospital admissions
- re-hospitalizations by providing effective transitions-in-care from hospital to home and stabilization and support in the home.
- institutionalization
- new or worsening and cascading health and behavioral health conditions exacerbated by emergencies



The Roadmap applies member-focused lessons from COVID-19 and other co-occurring and previous emergencies to contribute to a broad, effective, and sustained ability to plan, respond and recover from emergencies. This guidance is not an exhaustive list of promising interventions but provides actionable pathways that contribute to:

- creation, embedding and sustaining of customizable processes, procedures, protocols, policies, training, audits, exercises, and community partnerships (the who, what, where, when, why, and how)
- weaving in emergency practices as “front burner” priority issues and not separate projects to get to as time allows
- protecting members’ health, safety, and independence via improved planning for coping with, living through, and surviving emergencies
- decreasing the higher death rates among people with disabilities and older adults after large disasters
- applying lessons from previous emergencies
- designating a responsible cross-function interdepartmental health plan team
- fostering research to test for the evidence of the effectiveness of the best emergency member-centered interventions

The following are **chapters and sections** which offer new or revised details for how health plans’ emergency practices can be most successful. A roadmap offers directions and strategies for getting to your destination. These chapters are the main points on your map – places where you should stop, look around, notice what could be better while appreciating everything on the journey that concludes with healthy living for all, including people with disabilities. This Roadmap gives diverse health plans and their departments routes to navigate towards achieving that goal.

**Health plan leadership** motivates the workforce to create and embed resilient processes into successful member-centered health plans and emergency practices. These leaders can cement effective emergency planning and response. They can create the environments and motivation to sustain efforts by reinforcing, integrating, allowing sufficient time, and monitoring roles in the health plan organization.



Health plan leadership benefit most from a cross-functional management planning and response team that includes representatives from all departments touching the emergency system. This team needs the time, resources, responsibility to implement and sustain change efforts. These individuals should be directly involved and have the authority to make decisions, develop and enforce policy, and evaluate progress and performance.

There is much **case managers, care coordinators, community health workers, community partners, and contractors** can do to protect members' health, safety, and independence before, during, and after emergencies. This preparation involves mitigating against, rapidly identifying, and reacting to protect members from the failure of support systems. This includes loss of supplies, technologies, and customized environments that usually work in non-emergency times.

Specific roles of care managers and care coordinators include:

- assessment, triage, and stratification
- assisting members with emergency plans
  - connecting members to specific solutions and community resources
  - rewarding members for completing all elements of their emergency plans
- life-safety checks and addressing identified needs
- preventing and diverting unnecessary and inappropriate admissions to medical facilities and nursing homes
- advocating and combating healthcare providers' implicit disability biases regarding the quality of life of people with disabilities
- accessing and navigating the complex maze of disaster recovery assistance

**Valuable tools for staff** include scripts (dropdown menus, questions, probes, prompts, multi-pick options) to help ensure consistency when identifying risk factors and developing actionable member emergency plans. These scripts need to be integrated into service software and other tools. Scripts improve the focus on critical details and help staff avoid less effective and vague planning.



The more ambiguous the risk description, the more difficult it is to develop realistic plans. A critical task is reviewing and revising vague and unclear questions with more decisive high-risk characteristic questions and descriptions. These Indicators include general identifiers as well as emergency plans for helpers, communication, power outages, evacuation, and transportation.

**Member emergency communication** involves developing or identifying, and disseminating information for members, family members, personal assistance, and caregivers. Clear, concise content and messages provided before, during, and after an emergency helps members take protective health and safety steps. Member emergency communication involves:

- analyzing gaps in existing emergency content
- using standards and building blocks to apply to all channels and content
- offering information in useable and understandable formats
- helping members get, pay for, and use devices that enable internet connectivity
- employing multiple methods to measure success

Information disseminated must be tailored to the needs of members. General emergency preparedness information is relevant for everyone. Emergency preparedness information for the general population, however, is not always enough for people with disabilities. Materials can be more inclusive when they contain information focusing on specific functional needs, health, hearing, vision, mobility, speech, cognition, thinking, understanding, learning, remembering, no cost and low-cost preparedness strategies. These preparedness activities include identifying emergency helpers (support people) and evacuation plans, collecting emergency health information and emergency documents, discussing these plans with personal attendants, family and significant others, and practicing and updating plans to align with current health and functional needs.

Ensuring access to information involves using different ways to offer effective communication. Significant numbers of people can't receive or understand information due to limitations of seeing, hearing, speaking, reading, remembering, understanding, intellectual abilities, and language proficiency. Offering information in useable and understandable formats



helps reach people with various abilities, disabilities, ages, reading levels, learning styles, cultures, and native languages. Some people only receive their information orally or visually, and some use alternative formats (Braille, large print, disks, pictures/graphics/symbols, and audio) to access print materials.

Regardless of where the message originates, all health plan departments need to follow standards for accessible communication which contributes to reaching the broadest possible audience, increasing everyone's ability to use and understand the content. These standards are best understood and followed by establishing a messaging process that presents clear, uniform, and operational performance guidance. These standards should detail the who, what, where, when, why, how, and save time while preventing poor compliance, inconsistencies, and discriminatory practices. These are building blocks upon which accessibility compliance standards are created and followed by all staff responsible for member emergency communication. These building blocks and content standards need to include:

- use of clear and plain language content
- use reoccurring and reinforcing distribution methods using multiple channels
- distribution of information in usable formats
- policies, guidance, contract language, and training that requires posting of accessible website and social media content and involves captioned videos, inserting long descriptions of graphics, and using accessible pdf documents
- a rapid review internal process to check all content for accessibility before posting conducted by trained and experienced people, including member-users
- preventing the use of images that reinforce disability biases and stereotypes
- employ multiple methods to measure the success of member emergency communication

Accessibility and emergency planning, response, and recovery contract obligations must be delineated in **contracts and vendor agreements**. These obligations need to be integrated into all procurement processes, including new, renewed, and extended contracts. Contractors and vendors



include, but are not limited to health care providers, suppliers of durable medical equipment, consumable medical supplies, transportation, information technology, marketing, and social media content, member and provider education and training content, and related materials, clinical, social and community services.

All contractors and vendors need to have their emergency contract obligations delineated. Boilerplate, non-specific language carries a substantial risk of failure and a substantial risk of discriminatory response. Compliance doesn't happen through boilerplate language but through design and details of processes, procedures, protocols, policies, and training relative to an area of coverage. Accessibility assessments vary significantly with the nature of the service or product. The capacity to comply with contract terms increases substantially with precise compliance details. For example, all videos are open captioned in English and Spanish, member education content includes alternative formats (braille-ready, large print, digital, electronic, audio) and transportation services use wheelchair-accessible vehicles.

**Contracting with community-based organizations** is a vital way to augment a health plan's emergency member services. In addition, trusted community-based organizations that include known leadership and staff are often best positioned to reach health plan members in linguistically and culturally appropriate ways.

Health plans benefit from community emergency partnerships to maximize effective planning and response, especially in large emergencies when local governments are overwhelmed and state and federal backup takes significant time to arrive, organize, and respond. The benefits include:

- maintaining active connections with diverse community partners in planning, exercises, drills, response, and recovery activities
- organizing delivery of needed items
- coordinating life-safety checks by leveraging partnerships with organizations that maintain current lists of those who will be the most negatively and disproportionately affected, and need lifesaving, life-sustaining, and life-supporting assistance
- evaluating successful outcomes



Members of these partnerships include local community service providers who can complement and assist first responders. Lives saved or lost depend on readiness and relationships that typically take time to build and mobilize. Thus, community partnerships can maximize effective response, especially in large emergencies when local resources are overwhelmed. Successful collaboration between the private and public sectors helps sustain care during times of crisis and community-wide strain.

Health plans benefit from participation in community emergency-focused partnerships in multiple ways. Members of these partnerships include local community service providers who can complement and assist first responders, especially those led and/or staffed by people with lived disability experience.

**Workforce training** changes behaviors and increases skills, allowing employees to think on their feet during an emergency. Mentoring and providing feedback to employees is a crucial piece of this learning. Prevent the loss of investment in effective training by avoiding outdated learning and evaluation models. Emergency training should include:

- refreshing content and materials frequently
- training teams (not just individuals)
- elevating the importance of exercises
- spaced and reinforced interval learning
- placing greater or at least equal emphasis on just-in-time training
- using evaluation methods that measure performance, impact, and outcomes

There are many ways state and federal regulators, advocates, influencers, and other **drivers of change** can accelerate and increase the adoption of member-focused emergency health plan practices. Minimum and uniform effective and sustained member-centered emergency practice interventions are multi-prong and multi-level responsibilities. It takes sustained attention and political will.

In addition to the government, other organizations can exert their influence to push for change that fosters these emergency interventions. They include:





- accrediting organizations, standard-setting bodies, and quality assurance organizations
- disability-focused organizations
- disability-led organizations
- grant makers
- professional health organizations and trade associations

State statutory and regulatory requirements that include state contract content with health plans are essential to reinforce change. Unfortunately, state contracts are often vague or silent regarding plan member-focused emergency requirements. For example:

- “The state requires that Medicaid health plans to have a well-documented emergency plan in place for specific members.”
- “Assist enrollees who reside in their own home or family home with developing a disaster/emergency plan for their household that considers the special needs of the enrollee.”

State contracts must provide specific details so vague terms such as “well documented,” “specific members,” “emergency plan,” and “special needs” are not left open to ambiguous and imprecise interpretation.

Federal and state regulators should develop regulatory requirements that mandate vendors and providers who supply lifesaving, supporting, and sustaining therapies, equipment, and supplies (upon delivery, service, and repair) to instruct members on activating emergency procedures for the equipment or service. These instructions include alternative ways to safely power the equipment with clear verbal, online documentation, hard copy (including pictures) directions in usable and understandable formats and preferred languages.

State contracts, federal and state statutory and regulatory requirements include audits and accrediting certifications which can reinforce the details of effective practice. These requirements add specificity and permissions to such items as contracting with community-based organizations to augment a health plan’s emergency member services. Additional suggested requirements are detailed throughout the Roadmap.



In summary, the increasing scale and scope of emergencies appear to remain the “new normal.” The time is now to make changes to help members successfully cope with and live through these inevitable events.

Emergency planning is an ongoing iterative learning and continual improvement process. It is better to do something than nothing and to start somewhere. Use this Roadmap to evaluate current strengths and weaknesses, opportunities, and for setting priorities.

## Definitions

This definition section is intentionally at the beginning of the Roadmap because understanding the use of these definitions and descriptions is important to the use of the guidance.

**Disability-led organizations** - are those which are “for, of, by, and with” people with disabilities, including seeing, hearing, breathing, speaking, walking, moving, understanding, learning, mental health conditions, and chemical sensitivities, etc. They include organizations:

- staffed by people who have disability-lived experience, including knowing the details, diversity, nuances, and complexity of living with a disability firsthand that cannot be duplicated and are not always thoroughly understood by those without a disability. What looks vulnerable, fragile, and medically acute to the untrained eye is often just living with disability to those embedded in the disability service system.
- who have the skill sets and can apply the deep experience needed to begin to address the complexities of social determinants of health (such as quality of housing, access to transportation, availability of healthy foods, air, and water quality, and neighborhood crime and violence) through systemic advocacy and delivering support services
- who have a deep understanding of working with people with diverse functional needs in non-institutional, community-based settings, and the community services and benefit programs from which benefit them
- who have a majority of people with disabilities in leadership and decision-making positions, including paid staff, volunteers, and boards of directors



**Disaster and emergency** - are used interchangeably and refer to large emergencies. Disasters typically affect a large area, many people and often overwhelm local resources, involving state and federal agencies for backup assistance. Emergencies and disasters refer to natural, technological, or human-caused disasters, such as power outages, earthquakes, chemical spills, extreme weather, hurricanes, tornadoes, heat waves, tsunamis, terrorism, pandemics, wildfires, mudslides, floods, and droughts. The all-hazards emergency approach is defined by the Centers for Medicare and Medicaid Services as an “integrated approach to emergency preparedness planning that focuses on capacities and capabilities that are critical to preparedness for a full spectrum of emergencies or disasters.”

**Health plans** - are health insurance plans across all lines of business: employer-sponsored coverage, individual insurance market, and public programs (Medicare and Medicaid). Plans offer their members medical and wellness services ((e.g., weight management), smoking cessation). They include systems for delivering services such as Health Maintenance Organization, indemnity, Medigap, preferred provider organization, and point-of-service plans.

## Types of health plans:

**Special Needs Plans (SNP)** - Medicare SNPs are a type of Medicare Advantage Plan (like a Health Maintenance Organization or Preferred Provider Organization). Medicare SNPs limit membership to people with specific conditions or characteristics. Medicare SNPs tailor their benefits, provider choices, and drug formularies to best meet the needs of the groups they serve. (Special Needs Plans (SNP), 2021)

**Medicare Advantage Plans** - Medicare Advantage Plans, sometimes called Part C or MA Plans, are an all-in-one alternative to original stand-alone Medicare. Private companies approved by Medicare offer them. When joining a Medicare Advantage Plan, people still have Medicare. These “bundled” plans include Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance), and usually Medicare drug coverage (Part D). Most Medicare Advantage Plans offer coverage for things original Medicare does not cover, like some vision, hearing, dental, and fitness programs such as gym memberships or discounts. Plans can also choose to cover more benefits or tailor their benefit packages to enrollees with certain chronic conditions. (How do Medicare Advantage Plans work?, 2021)



**Hospital at-Home** - is an innovative care model for adoption by health care organizations that provides hospital-level care in a member's home as a full substitute for acute hospital care. (Hospital at Home, 2021) (Hospital at Home, n.d.)

**In lieu of services (ILOS)** – are services or settings a health plan substitutes for a similar service covered under the contract. These services provide considerable flexibility for health plans beyond services defined in the Medicaid state plan to address social needs.

**Leadership** - health plan administration and management, including the health plan's board of directors or trustees.

**Lifesaving, life-supporting, and life-sustaining** - terms used interchangeably in this Roadmap to refer to saving, protecting, and extending life. Every individual has diverse and different timing needs regarding the loss of medications, devices, equipment, supplies, temperature-controlled environments, personal attendants, and caregivers. These needs may not be an immediate threat to life but can quickly become a threat to life over a few hours or days.

**Long-term care facility** - a facility that provides rehabilitative, restorative, and/or ongoing care to residents in need of assistance with activities of daily living. Long-term care facilities include nursing homes, rehabilitation facilities, inpatient behavioral health facilities, group homes, assisted living, and long-term chronic care hospitals.

**Long Term Services and Supports (LTSS)** - encompass a wide array of ongoing services and supports designed to meet the physical, cognitive, behavioral, functional, environmental, social, and personal care needs of individuals across the lifespan who are living with chronic conditions, functional limitations, and disabilities. For people accessing LTSS, various interrelated factors often determine health and quality of life; therefore, states are looking to connect healthcare and supportive services to improve quality of care and overall health while managing costs. LTSS targets individuals with complex medical issues, physical disabilities, intellectual and developmental disabilities, mental health and substance use conditions, and children in foster care.

Half of all states currently provide Medicaid coverage for long-term services and supports (LTSS) through contracts with Medicaid-managed care



organizations. More than 12 million Americans use LTSS. People with functional or cognitive limitations of all ages, including children, adults under 65 with disabilities, and older adults, require LTSS to maintain independence and high quality of life in their homes and communities or an institutional setting. While older adults represent most of the population who use LTSS, nearly half of all people who use LTSS are under 65.

LTSS includes a range of services from nursing home care to assistance provided in the home with activities of daily living (ADLs), such as bathing, dressing, and eating, adult daycare, home health aides, homemaker and personal care services, community residential services, respite care, transportation, and home-delivered meals. LTSS encompass varying ongoing services and supports designed to meet the physical, cognitive, behavioral, functional, environmental, social, spiritual, and personal care needs of individuals across the lifespan who are living with chronic illness, functional limitations, and/or disabilities. For people accessing LTSS, multiple interrelated factors often determine health status and quality of life.

**Managed Long-Term Services and Supports (MLTSS)** - assist states in delivering high quality services at the same or lower cost as the fee-for-service system with a particular focus on ensuring beneficiaries quality of life and ability to live in the community instead of an institution.

Individuals benefitting from LTSS include those with:

- complex medical issues
- physical disabilities
- speech and language disabilities
- intellectual and developmental disabilities
- mental health disabilities
- substance use issues
- children in foster care
- dually eligible members (Medicare and Medicaid)

(National MLTSS Health Plan Association, n.d.)

**Member** - includes enrollees, participants, beneficiaries, customers, subscribers, users, people with disabilities, and others with access and functional needs.



**Member-facing** - interactions and communicating directly with members of a health plan.

**Patients** - describes members only when they are being seen at a medical appointment, undergoing a test or procedure, or admitted to a medical facility for inpatient care.

**People with disabilities and others with access and functional needs** - includes broad and diverse groups of people who also directly benefit from physical, communication, and program access. This includes people who may not identify or think of themselves as having a disability or may or may not meet the definitions of civil rights laws or some of the other 60 plus diverse definitions of disability used in the United States. This population includes people who experience limitations in behavior, walking, balancing, climbing, seeing, reading, hearing, speaking, understanding, and remembering. These diverse populations are typically under-recognized and undercounted in census and data surveys.

**Personal assistance** - includes personal care attendants, direct support professionals, home health aides, private duty nursing, homemakers, chore assistance, and companionship services. Depending on the state and health plan, some of these services are directed by the member and not an outside contractor or vendor.

**Population Health** - looks at all groups within a given population. Unlike other metrics that use an average, population health considers the health of everyone. So, while the majority of people may be healthy, population health does not reflect that until the minority is also healthy. Population health examines the distribution of such outcomes within a group. These groups are often geographic populations such as nations or communities, but can also be other groups such as employees, ethnic groups, people with disabilities, prisoners, or any other defined group. The health outcomes of such groups are of relevance to policy makers in both the public and private sectors.

Note that population health is not just the overall health of a population but also includes the distribution of health. Overall health could be quite high if most of the population is relatively healthy—even though a minority is much less healthy. Ideally, such differences would be eliminated or at least substantially reduced. (David A. Kindig, n.d.)



**Resilience** - is the ability to cope with, live through, and survive emergencies, related stress, and trauma. Resiliency includes protecting one's safety, health, and independence and adapting and recovering from difficult situations.

**Social determinants of health** - are conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of-life risks and outcomes such as quality of housing, access to transportation, availability of healthy foods, air, and water quality, and neighborhood crime and violence. (CDC Centers for Disease Control and Prevention, 2021)

**Stakeholders** - are those entities in the organization's environment that play a role in an organization's health and performance or that are affected by an organizational action.



## Chapter 1: How to Use this Roadmap

All readers should start with the Definitions and Purpose and Background chapter. Then read the entire document or focus on those sections that address your role in or with health plans and the impact your job, department, or organization expects to have on member emergency outcomes.

In this report, health plans refer to health insurance plans across all lines of business, employer-sponsored coverage, individual and group insurance market, and public programs (Medicare and Medicaid). Plans offer payments or reimbursements for medical services to their members and include models for delivering services such as Health Maintenance Organizations (HMO), indemnity, Medigap, preferred provider organizations, and point-of-service plans.

### **Environment of constant priority overload**

Some will see this Roadmap content as aspirational and overwhelming, especially in a health plan environment of constant priority overload. It can feel hard to prioritize planning when day-to-day workloads include:

- organizational growth and changes
- contractual limitations
- regulatory audits and reporting requirements
- new state and federal initiatives with aggressive implementation timelines
- staffing shortages and turnover
- workload priorities

This document does not intend to overwhelm but to provide actionable ideas and steps to foster members' emergency-related health, safety, and independence. Given the reality of today's health plan workplace, narrow bandwidths, and full plates, creating, promoting, sustaining, and embedding new values and practices into the cultural fabric of health plans must happen in incremental steps. Knowledge of the big picture helps, but everyone in a health plan must understand what actions and skills are needed to contribute to successful outcomes.





## Iterative and continual improvement process

Emergency planning is an ongoing iterative learning and continual improvement process. (See Chapter 3. Leadership: Roles of an Emergency Oversight Team) It is better to do something than nothing and to start somewhere. Jargon says it well: start small, grab the low-hanging fruit, hit the softballs, make small dents, and chip away at objectives.

Health plans can use this report as a basis for evaluating current strengths and weaknesses, opportunities, and setting priorities:

- assign different areas needing work to department staff as specific leadership projects
- continually assess progress

## Planned future checklist

A future activity of the Roadmap project will be to develop a shorter, easily customized health plan checklist as a companion piece. This checklist will include actionable steps incorporating elements from this comprehensive and lengthy report.

## Audiences

This publication addresses the concerns of a wide range of stakeholders, including:

- frontline health plan staff and leadership
- medical service providers and home and community-based services
- provider organizations such as adult day programs, home health care services, and community-based agencies

These concerns include helping members before, during, and after emergencies. More specifically, the roles and possible actions of...

- accrediting organizations, standard-setting bodies, and quality assurance organizations
- disability-led, disability-focused, and community-based organizations



- emergency management consultants
- emergency managers and planners
- Federal and state legislatures
- Federal, state, and local health agencies
- grant makers
- health plan leadership and staff
- researchers

## Anticipated first adopters

All lines of the health plan business are included in this Roadmap. However, this report anticipates that the first plans to adopt these recommendations are those leading-edge health plans and those most receptive to its guidance and advice, such as:

- plans that have strong “perceptions of threat” and operate from the “not if, but when” attitude about the risks of reoccurring disasters
- plans located in high hazard threat and disaster probability areas
- plans with natural connections with members who tend to have the highest personal risk factors and experience disproportionate negative effects by service disruptions. For example, children, adults with disabilities, and older adults who need assistance in activities of daily living, use a variety of services and supports over an extended period and multiply marginalized individuals (people in poverty, non-English speakers, Black, Indigenous and People of Color)
- plans offering comprehensive, coordinated care such as long-term services and supports that help members remain independent in their homes and communities through increased access to home and community-based services (HCBS), resulting in improved health and quality of life outcomes
- plans meeting the clinical and non-clinical needs of high-cost, high-need managed care members through interdisciplinary, high-touch, and person-centered service
- Medicare-Medicaid plans, Medicare Special Needs plans, managed care long-term services and supports plans and PACE (Program of All-inclusive Care for the Elderly)



**Note:** Rates of insurance coverage are generally comparable between disability and non-disability populations, but the nature of coverage differs. Approximately 75% of people without disabilities have private health insurance, but fewer than 50% of people with complex limitations (severe disabilities) are privately insured. Furthermore, although public insurance provides coverage for many people with disabilities, it does not cover all people, and people with mental health disabilities feel the greatest gaps; 28% are uninsured. Even with insurance, people with disabilities are much more likely (16% vs. 5.8%) to miss getting needed care because of the cost. (Alterman & Bernstein, 2008) (Centers for Disease Control and Prevention. QuickStats: Delayed or forgone medical care because of cost concerns among adults aged 18-64 years, by disability and health insurance coverage status, 2009) (Disability and health state chartbook: Profiles of health for adults with disabilities, 2006)

These health plans are in the unique position of proactively addressing and protecting the narrow margins of health resilience, safety, and independence of their members before, during, and after an emergency.

## Chapter 2: Purpose and Background

### Purpose

This Roadmap aims to foster and embed resilient processes into member-centered health plans' emergency practices. In the United States, people with disabilities and older adults are two to four times more likely to die or sustain a critical injury during a disaster than people without disabilities. (See below, Background)

Health plans are often overlooked as essential partners before, during, and after emergencies. Yet, more than any other service system, health plans, public and private, serve most people with disabilities in the United States. Health plans can do much to protect members' resilience, health, safety, and independence and prevent or mitigate the cascading exacerbation of typically well-controlled chronic health conditions.

This guidance weaves findings from interviews, organizational learning consultations, guidance reviews, and subject matter expert reviews of the Roadmap draft into elements of practices and interventions that foster strengthening lifesaving and life-sustaining member interventions. These chapters identify interventions, practices, and roles:

- Leadership
- Case management, care planning, and care coordination.
- Member emergency communication
- Contractor and vendor agreements
- Community partnerships
- Workforce training
- Policy change and other points of influence

This report applies member-focused lessons from COVID-19 and other co-occurring and previous emergencies to contribute to a broad, effective, and sustained ability to plan, respond and recover from emergencies. This guidance is not an exhaustive list of promising interventions but provides actionable pathways that contribute to:

- applying and accelerating the embedding and sustaining of customizable processes, procedures, protocols, policies and training



audits, exercises, and community partnerships (the who, what, where, when, why, and how)

- designating a responsible cross-function interdepartmental team rather than depending on a single person
- weaving in emergency practices as “front burner” priority issues and not separate projects to get to as time allows
- creating the environment and motivation to sustain efforts through reinforcing, integrating, allowing time for, and monitoring roles
- protecting members’ health, safety, and independence via improved member planning for coping with, living through, and surviving emergencies
- lessening the risk among people with disabilities who are at higher risk and disproportionately impacted by large emergencies
- decreasing the higher death rates among people with disabilities and older adults after large disasters
- acknowledging that the needs of disaster-impacted people far outweigh the collective resources and capabilities of the government (especially in large-scale events where the need for member assistance is more than usual, immediate and throughout the long-lasting recovery process)
- accelerating the speed at which health plans activate their emergency response plans as a direct way to increase positive member outcomes
- preventing institutionalizing in emergencies of people with disabilities who lived in the community
- resisting the inevitable and pervasive “fade factor” (which is the typical human emergency cycle -- a short-lasting burst of passionate advocacy and the renewed vigilance to prepare for next time)  
Renewed vigilance is followed by a rapid melting away as time passes, and other compelling priorities compete for scarce time, attention, and budget
- fostering research to test for the evidence of the effectiveness of the best emergency member-centered intervention



## Filling the guidance gap

Filling the gaps between what is known regarding emergency planning, response, and recovery and what gets done is critical. This guidance aims to begin to fill these gaps. The COVID-19 pandemic is an atypical emergency because its long-playing timeframes allowed time to innovate, test, and course-correct for various responses. Usually, this luxury of time in emergencies is not an option.

Much content exists on pandemic health plan innovation and promising practices. However, there is very little content on applying and retooling these practices for permanent and quick unpacking and deployment during inevitable future emergencies. Given the increasing frequency, intensity, scale, duration of public health, climate-related, natural and human-caused, old and deteriorating infrastructure, and other large emergencies, attention to creating, embedding and sustaining these practices is critical.

Smart people learn from their mistakes. But the real sharp ones learn from the mistakes of others. Brandon Mull, bestselling author

(Raina M. Merchant, et al., 2015)

(Answering the Call: Health Insurance Providers Act Swiftly as Part of the COVID-19 Solution, 2020)

(Health Insurance Providers Respond to Coronavirus (COVID-19), 2021)

(Archibald, 2021)

This report does not exempt other organizations from developing and implementing their emergency practices for the people they support. This Roadmap recognizes that health plans need to work in partnership with community organizations. Relationship building through community partnerships helps all partners be more effective and do better together. (See Chapter 6. Community Partnerships)

## Health Plans have critical roles in emergencies

Health plans can strengthen their critical emergency roles in addressing and protecting their members' resilience, health, safety, and independence. In emergencies, health plans can prevent or mitigate the cascading negative



emergency effects of typically well-controlled chronic health conditions. Like a house of cards, the precarious balance can easily be disrupted or collapse. Targeted prevention includes protection from the failure of:

- personal support systems during disasters
- loss of supplies
- loss of medications
- loss of technologies
- loss of customized accessible environments
- equitable access to disaster response programs, services, and activities

History confirms that health plans are inundated by immediate, lifesaving, and life-sustaining needs of people they serve during large emergencies. These needs are especially true for high-risk and disproportionately negatively impacted members of health plans who will need assistance more than ever, immediately and throughout the recovery process – which is often long-lasting and unexpected.

The evidence is clear that most, if not all, of the health plans' roles and interventions covered in this document have an impact across hazards, emergencies, disasters, and changes in settings. Moreover, the consequences of emergencies for people with disabilities and others with access and functional needs are the same regardless of the type of emergency: power outages, earthquakes, chemical spills, extreme weather, tsunamis, terrorism, pandemics, and wildfires, mudslides, floods, etc. Therefore, health plans should develop an all-hazards approach to readiness which involves broad enough practices to apply to all disasters or emergencies.

## **Better health, resiliency, and health cost savings**

Joyce Delarosa uses a power chair and lives in public housing. During hurricane Sandy, she notified the city officials and the utility company that she used an oxygen machine and needed electricity to survive. However, she was told that there was no plan for emergency generators, battery packs, or other supplies. She called the city to get help, and she got no response. She



was trapped in a high rise with no oxygen for three days when she was finally found and evacuated for emergency medical attention.

Embedding emergency practices and services outlined in this Roadmap can lead to better health, resiliency, and health cost savings, especially for high-risk individuals who live with complex health care conditions. These practices prevent or reduce:

- use of ambulances
- emergency department visits
- hospital admissions
- re-hospitalizations by providing effective transitions of in-care from hospital to home and stabilization and support in the home
- institutionalization
- new or worsening and cascading health and behavioral health conditions exacerbated by emergencies

## Background

### **High death rates and injuries among people with disabilities**

Indisputable evidence documents and undercounts high death rates among people with disabilities of all ages and older adults after large disasters. In the United States, people with disabilities and older adults are two to four times more likely to die or sustain a critical injury during a disaster than people without disabilities. (Disaster Preparedness and Response: The Special Needs of Older Americans, 2017)

This death rate is much higher because of increased mortality rates in the months after disasters. These increased deaths are due to a cycle of worsening conditions such as psychological, social, health, and physical stressors. In addition, higher mortality rates are often a consequence of the interruption of power, especially for those dependent on life-sustaining equipment and limited access to critical supplies, mobility and communication devices, durable medical equipment, medications, oxygen, health care (dialysis, chemotherapy, other infusion therapies), home health care and attendant services.





Comparisons of death rates in a disaster year compared to previous years repeatedly show that many more deaths occur in the disaster years. Unfortunately, disaster deaths are a highly politicized issue. Generally, governments want to minimize numbers to make leaders and response systems look good, and thus event-related death rates are under-counted. Instead, direct causes tend to get counted: drownings, falling objects, the heroism of responders, and other directly observable causes, such as severe injuries leading to subsequent death.

The data is inadequate regarding emergency planning with and for people with disabilities, but what is available indicates this is an exceptionally high risk for this disproportionately impacted population. For example, during Hurricane Katrina, 38% of people who did not evacuate to safety had a mobility disability or were a personal assistant and care provider for a person with a disability. (Survey of Hurricane Katrina Evacuees, 2005)

### **Continuity of Operations Plans (COOPs)**

There is a tendency for health plans to put more power and support in their “Continuity of Operations Plans” (COOPs) than in their member-centered emergency plans. Although essential, the focus here is not on “Continuity of Operations Plans.” COOPs do not focus on the needs of members with disabilities. There is a great deal of available COOP guidance and regulatory requirements in the marketplace now. COOPs focus on health plan overall emergency elements such as: ensuring service continuation, staffing, communication, supplies, decision-making, access to data, alternate and temporary work locations, mutual aid, communication of emergency messages, and updating emergency plans. (Ream, 2011)

### **Nursing Homes**

This Roadmap does not provide a detailed plan for emergency issues regarding residential care facilities. Deaths in nursing homes accounted for more than a third of COVID-19 deaths in the United States. This critical and complex issue merits a lengthy exploration and separate document. Examination and needed policy changes must stop the institutional bias inherent in all health care funding and fully fund home and community-based services (HCBS). HCBS can be provided for less than half the cost of traditional institutional care. (Home and Community Based Services, 2021)



(Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters, 2019)

(Downard, 2021)

## **Implementation barriers: Magical thinking**

### **No health plan resides in a disaster-free zone**

Widespread magical thinking and all too common assumptions mistakenly assume that government will take care of community members in an emergency. Unfortunately, this belief leads to a mismatch in expectations among the community, health plans, and local, state, and federal governments. While no plan exists in a disaster-free zone, each health plan should develop plans specifically responsive to the common emergencies occurring in their region. Also, it is important to factor into this planning those emergencies that may not be probable but are still possible.

The reality is that the needs of disaster-impacted people far outweigh the collective resources and capabilities of the government, especially in large-scale events. Relying on 911 as a member's backup or emergency plan during a community-wide emergency is a predictable point of failure. Government emergency service providers need knowledgeable and prepared partners to help with the specific and often complex health maintenance needs of people with disabilities supported by health plans.

Health plans that think "not if, but when" do better in emergencies. These health plans acknowledge that their members live in high hazard threat and disaster probability areas. Because of this, these health plans have policies, training, processes, procedures, and protocols to implement a robust response.

Other plans are in areas where large emergencies occur less often. Nevertheless, preparation everywhere is critical -- be it for climate change, weather, or power-related emergencies.

What is essential is how health plans engage and leverage their resources to contribute to an effective response. In addition, government and community emergency services need help with the specific and often complex needs of the people health plans serve.



Emergency personnel have little to no training in disability-related assistance. As a result, even well-intentioned emergency service personnel cannot deal with the many needs of people with disabilities adequately.

Government can and will continue to serve disaster survivors. However, we fully recognize that a government-centric approach to disaster management will not be enough to meet the challenges posed by a catastrophic incident. That is why we must fully engage our entire societal capacity.

Craig Fugate, FEMA's past administrator

History confirms that health plans are inundated by immediate, lifesaving, and life-sustaining needs of people they serve during large emergencies. These needs are especially true for high-risk and disproportionately negatively impacted members of health plans who will need assistance more than ever, immediately and throughout the long-lasting recovery process.

Mary Connor is blind and lives in an evacuation zone. She received a piece of paper instructing her to evacuate as Hurricane Irene hit her area. She couldn't read the paper. She called the public information line but couldn't get through to an operator.

Health plans should be on the front lines of protecting, addressing, and maintaining the critical health needs of members, before, during, and after an emergency.

June Isaacson Kailes, Disability Policy Consultant

The speed at which health plans activate their emergency response plans correlates directly to life-sustaining outcomes for many who are disproportionately affected. Rapid health plan response can also stop the disturbing trend of institutionalizing people with disabilities who were living in the community. This institutionalization happens because of planning failures, including lack of health care options, accessible emergency and transitional-shelters, accessible housing options, and difficulties these individuals have in accessing and navigating the complex maze of disaster recovery assistance. (See Chapter 4. Case Management, Care Planning and Care Coordination: Preventing and diverting unnecessary and inappropriate admissions to medical facilities and institutionalization. (Roth, Kailes, & Marshal J.D., 2018)



## **Fade factor**

Lessons from prior emergency responses are often lost unless concerted efforts are made to apply and maintain them. Applying lessons from previous mistakes can make the difference between life and death for people with disabilities and others with access and functional needs. It's about impact and outcomes. The goal is not just lessons observed, documented, or heard about, but lessons repeatedly applied, so they can eventually be claimed as lessons learned. It is easy to anticipate and produce a long list of lessons from past emergencies. However, it is much more challenging to move from minimal to maximal long-term solutions and continued work to create, operationalize, embed, and sustain the effort to get better outcomes.

It is difficult to counteract the typical human cycle of a short-lasting burst of passionate advocacy and the renewed vigilance to prepare next time. Renewed vigilance is followed by a rapid melting away as time passes, and other compelling priorities compete for scarce time, attention, and budget. Finally, people relax, take a breath of relief, refocus, and resort to the magical thinking that it won't be that bad next time, or it won't happen again.

This Roadmap offers action steps to resist this inevitable and pervasive "fade factor." Health plans, especially, must guard against the fog of complacency as some denial settles back into place. It is about preventing the work done to improve disaster response from fading to the point that it is an undetectable imprint in the sand. Instead, this content offers pathways to commit to laying a blueprint for building a transformational, indelible, concrete mark in that sand - building systems of recovery and response that work for everyone.

## **Sustained commitment to applying lessons**

Use the Roadmap to integrate ideas and processes into health plans, policies, procedures, protocols, community partnerships, training, exercises, and audits. Once consistently and repeatedly applied, we can claim them as lessons learned. The recommendations aim to accelerate better outcomes by embedding and sustaining customizable processes. However, real progress depends on a sustained commitment to ensuring that the fade factor does not occur in health plans.



## Research and methods

During 2020 through 2021, a multipronged approach to information gathering for this project included:

- 66 key informant interviews
- five organizational learning consultations with home health, health plans, and health plan companies
- review of online guidance content from government, researchers, and trade associations
- 26 subject matter experts, including 19 interviewees, reviewed and commented on the draft report and offered valuable suggestions regarding organization, accuracy, clarification, and definitions

### Interviews

Sixty-six (66) interviews were conducted by Zoom or phone. Open-ended questions encouraged interviewees to respond conversationally and generate new ideas. Interviews ranged from 30 minutes to 1 to 2 hours. (See Appendix C: Interview Questions)

Fields represented by interviewees (some key informants represented more than one discipline and organization):

- 24 - Health plans
- 16 - People with disabilities
- 13 - Contractors and consultants
- 13 - Disability-led organizations
- 13 - Researchers
- 7 - Emergency management
- 5 - Government agencies
- 3 - Foundations
- 1 - Accrediting and standard-setting organization

The feedback received during these interviews helped formulate good practices, perceptions, opinions, policy issues, and dissemination strategies related to:



- member-focused roles of health plans before, during, and after emergencies
- identified gaps in service and responses in emergencies
- existing member-centered emergency health plan guidance
- disseminating this project's findings and report (Roadmap)

## **Organizational consultations**

The project also benefitted from consultations with:

Two health insurance companies:

- Anthem is the largest for-profit managed health care company in the Blue Cross Blue Shield Association
- Centene Corporation is the largest Medicaid managed-care organization in the U.S. It is a healthcare insurer that focuses on managed care for uninsured, underinsured, and low-income individuals.

Two health plans

- Blue Shield California Promise Health Plan is a managed care organization wholly owned by Blue Shield of California, offering Medicaid, Medicare, and Cal MediConnect Plans serving Los Angeles and San Diego Counties.
- Inland Empire Health Plan is one of the ten largest Medicaid health plans and the largest not-for-profit Medicare-Medicaid plan in the country. It serves California's Riverside and San Bernardino counties.

And one home health agency which is a program of The Independence Center of Colorado Springs serving multiple counties in Colorado.

Regular meetings with these organizations occurred between November 2020 and September 2021. Meeting topics consisted of:

- each organization choosing the areas of improvement they want to work on
- technical support available from the project lead



- tracking progress
- problem-solving
- course corrections when needed
- next steps
- mapping additional mid-term and long-term plans

Each organization selected areas that it needs to strengthen. These areas included:

- care planning and care coordination
- life-safety checks
- member emergency communications
- member emergency plans
- community partnerships
- enterprise-wide focus

In addition, each organization agreed to:

- meet regularly with the project lead
- submit a report regarding challenges, lessons learned and how to apply them, successes, failures, and plan details
- review a draft of this Roadmap

These groups were motivated to participate because

- they work in areas with a strong “perception of threat” and operate from the attitude of “not if, but when” risk of real and reoccurring disasters. These plans reside in and serve people in high hazard threats and disaster probability areas.
- they received and benefitted from technical support during the project, including resources, materials, and training
- they increase their competitive advantage in future state contract opportunities



## Chapter 3: Leadership

### Reinforcing and sustaining the commitment

Health plan leadership includes executive teams and department managers. This group can motivate their workforce to foster, create, and embed resilient processes into member-centered health plans emergency practices. These practices include protecting members' resilience, health, safety, and independence and preventing or mitigating the cascading exacerbation of typically well-controlled chronic health conditions.

As mentioned earlier, there is a tendency for health plans to put more power and support into their Continuity of Operations Plans than into their member-centered emergency plans. Emergency issues often get sidelined as a project "to get to" as time allows, instead of hardwiring these elements into all processes, procedures, protocols, policies, and training.

Leadership has a pivotal role in guarding against what gets in the way:

- can't do – "We don't have enough staff, time, or funding."
- won't do – "We have no way to enforce this. No one will check."
- don't know how or what to do – "Frankly, we don't know how to do this. Where does the help come from?"

Here is an example of staff complaints about barriers:

We need administrative buy-in. I'm told to do what is required but they don't find it as urgent or important as I do. For example, I got a lot of resistance about our workplace violence and active shooter trainings. They didn't think it was necessary until I showed them the [OSHA \[Occupational Safety and Health Administration\] regulations](#) and said, "You know you can get sued for this if something were to happen."

Because they don't believe anything is going to happen...they don't see the need for the trainings. But when it became evident that it is required, then I can do it if it does not take a lot of staff time or cost. I must really work hard to get approval for those kinds of things. Emergency Preparedness Lead, Health Home Director, CCM, and Chronic Pain Case Manager, Rural, FQHC, CHC





(Disaster Case Management and Individuals with Disabilities, 2010)

Leadership plays the most critical role in setting expectations and weaving emergency roles into the organization's cultural fabric. Leadership cements the emergency planning and response system by effective training, evaluation of employees and department performance, and reinforcing, integrating, allowing time for, and monitoring planning, response, and recovery roles. Specifically, leaders

- counteract the fade factor (See Chapter 1. Background and Purpose: Fade Factor) by frequently reinforcing the organization's commitment over the long run using multiple communication channels
- reinforce that emergency planning, response and recovery is not a task, not an "emergency preparedness month" activity, and not a separate project to get to as time allows; it is a critical ongoing part of how the health plan system works
- inspire a shared cultural attitude about the importance of being effective health planning partners in an integrated system
- institute a wholistic approach by ensuring that all organizational players know the big picture of what should happen in a disaster and the roles each person and department play in an effective response.
- commit to specific planning for the needs of members with disabilities (Disaster Case Management and Individuals with Disabilities, 2010) (Medical Surge and the Role of Health Clinics, 2018)

Leadership defines what the future should look like, aligns people with that vision and inspires them to make it happen despite the obstacles.

John P. Kotter, famous thinker on leading change

Reference

John P. Kotter, John J. Gabarro (2015). "Tools to Change Your Organization: The Change Leadership Collection (2 Books)", p.28, *Harvard Business Review Press*



## Time

As is true of anything worthwhile, health plans must dedicate time to making changes that will improve member outcomes and employee/department performance. Moving away from the “task” or “one-time” mentality means shifting organizational culture so that all employees understand the value and importance of their emergency planning, response, and recovery roles.

It is a small part of my job. We are small; we don't have a dedicated person doing disaster planning; it probably represents only about 5% of my effort now.

Director of Quality and Risk Management and Emergency Preparedness  
Lead, Rural, FQHC, CHC

Leaders must anticipate the roadblocks, choke points, and barriers from staff and have methods to prevent them. These methods require devoting time to communications, performance evaluations, and reward excellence in reinforcing the desired change. (Medical Surge and the Role of Health Clinics, 2018)

## Roles of the Emergency Oversight Team

Health plan leadership should create a cross-functional management planning and response team that includes representatives from all departments touching the emergency system. Do not leave this to one person! Instead, appoint an emergency oversight team of appropriate leaders who are publicly recognized and have the time, resources, authority, and responsibility to implement and sustain change efforts. These individuals should be directly involved and have the authority to make decisions, develop and enforce policy, and evaluate progress and performance. The team's roles include:

- authorizing and activating immediate emergency response plans and teams to maximize the best outcomes for members
- setting up a “command center” staffed by key leadership and clinical staff that quickly finds and uses (pre-developed) response checklists to identify needs, challenges, and issues as they arise and to enable quick, well-coordinated responses



- creating plans, processes, and procedures that detail rapid workable functions inclusive of realistic and back-up systems
- assigning specific tasks to be studied and improved upon using continual quality improvement projects.

Producing major change in an organization is not just about signing up one charismatic leader. You need a group – a team – to be able to drive the change. One person, even a terrific charismatic leader, is never strong enough to make all this happen.

John P. Kotter

- working to ensure interoperability and compatibility of software programs to share member information and strengthen a coordinated response across health plan departments
- connecting all the threads of the many departments that touch members:
  - appeals and grievance
  - behavioral health
  - care coordinators and case managers
  - call centers
  - community health workers
  - community partnerships
  - compliance
  - contractors and vendors
  - customer service
  - delegated services and agreements
  - management information systems, Information technology
  - long term services and supports
  - medical services
  - member communication
  - member education
  - population health and social determinants of health projects
  - provider communication
  - provider education
  - pharmacy standards



- provider relations
- quality improvement
- social services
- transportation
- workforce training
- identifying members with disabilities, their emergency needs, and solutions
- creating feedback loops for staff, members, and stakeholders that are easy to use and produce valuable information for current and future quality improvement efforts, e.g., devoting adequate time to feedback sessions during and after emergency practice implementation, training, exercises, and opportunities to discuss new learning to apply. Methods such as focus groups, surveys, debriefs are critical to understanding and making changes.



- putting in place open feedback loops and monitoring the emergency functions detailed in these Roadmap Chapters: Case Management, Care Planning, and Care Coordination, Member Emergency Communication, Contractor and Vendor Agreements, Workforce Training, and Policy Change and Other Points of Influence
- integrating expectations of performance into job descriptions, interviews of potential employees, performance reviews, and departmental reports of outcomes and evaluations
- avoiding repeated mistakes and “reinventing the wheel” by applying lessons in a continuous improvement process.
- devoting significant time to embedding the lessons by revising and updating plans, policies, and checklists
- seeking stakeholder feedback that yields value versus going through the motions to fulfill a legal mandate to be endured, simple compliance, or checking the box. The objective is to promote safe environments where individuals don’t tell you what you want to hear; they tell you what you need to hear. Include disability advocates who

can share feedback that some members may fear sharing or be reluctant to share.

The key to successful integrated care - especially for older adults and people with disabilities - is active, meaningful consumer engagement since consumers and their caregivers are at the heart of everything we do.

Dr. Robert J. Master Former CEO, Commonwealth Care Alliance

(Major Stakeholders of Health Care System pwrpnt, n.d.)

- meaningful feedback can help plans fine-tune their emergency assistance by:
  - rethinking organizational priorities
  - addressing current challenges and problems
  - developing new initiatives
  - collaborating to create active, ongoing conversations that benefit members, consumers and their caregivers, health plans and provider groups
  - providing information regarding stronger and weaker aspects of care delivery that impact the system's bottom line and consumers' health outcomes and quality of life.
- contracting with community-based organizations to multiply resources for deliverables (See Chapter 5. Contractor and Vendor Agreements: community-based organization (CBO) contracting opportunities)
- targeting and funding of initiatives and pilots integrated into health equity, social determinants of health, in lieu of services, and population health projects (See chapter 8. Policy Change and Other Points of Influence: Federal and state regulators - development of meaningful metrics)
- understanding federal emergency reimbursement policies to pre-plan with the state to be eligible for and ready to bill for some emergency services costs
- encouraging and incentivizing researchers, including contractors and graduate students, to test for the evidence of the effectiveness of



emergency member-centered interventions. (See Chapter 9. Policy Change and Other Points of Influence: Meaningful metrics)

- activating waivers by working with the state health department to submit waivers that allow for a nimble, quick, and flexible response to provide supplemental services to prevent the delay of vital assistance. For example, Home and Community-Based Services (HCBS) 1915(c) Appendix K waivers... provide a stand-alone option for states to use during emergencies to request amendments to existing programs that support emergency response actions for the HCBS population. Certain other activities may require different authorities, such as Section 1115 or Section 1135.
- activate flexibilities to broaden covered services to include specific non-medical services and avoid restrictive protocols that delay vital care and services. Emergency services, for example, could involve securing items such as portable generators and personal protective equipment. Additional examples of flexibilities include:
  - creating emergency service funds used for quick expenditures to meet immediate member needs without having to wait for an approval process; in other words, for every covered benefit, there should be an emergency authorization implementation plan
  - allowing funding of emergency equipment such as backup home and shelter deliveries, batteries, generators, fuel, hotel stays, in-term mobility equipment, sliding boards, shower chairs, food delivery, air conditioners, reconstruction of ramps, etc.
  - expanding use of home-based care and remote monitoring practices such as “Hospital in the home,” “Hospital without walls,” telehealth, and telemedicine
  - planning for care and mutual aid for members needing to evacuate out of the area or out of state, including plans to access services offered through mutual aid agreements with other health plans and out-of-network services
  - preplanning for the ability to quickly share member health information when it is critical to a member’s life and essential continuity of care, especially when seeing out of network providers



- expediting approvals and being ready to implement service (with appropriate controls) outside of the usual procurement process, such as:
  - use of out-of-network providers when medically necessary to prevent members from experiencing significant delays in care
  - temporary incentive rates to retain and or recruit new people to fill gaps in the caregiver workforce
  - pay families to serve as personal attendants to alleviate the inevitable emergency-related shortages in the workforce (consumer-directed and agency-controlled homecare)
  - authorize equipment replacement
  - suspend timelines for re-determination processes
  - waive medication delivery costs and restrictions regarding filling emergency prescriptions
  - access to non-emergency transportation
  - allow for crisis intervention decisions during non-working hours

(Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers, n.d.)

(Home and Community Based Services, 2021)

(Medical Surge and the Role of Health Clinics, 2018)

## Chapter Summary

Health plan leaders motivate their workforce to foster, create, and embed resilient processes into member-centered health plans emergency practices. These leaders can cement emergency effective planning and response by creating the environment and motivation to sustain efforts by reinforcing, integrating, allowing time, and monitoring roles.



## Chapter 4: Case Managers, Care Planning and Care Coordination

Disasters are **always** inclusive. Response and recovery are not unless we plan for it! Different populations have different needs. June Isaacson Kailes

Case managers, care coordinators, community health workers, community partners, and contractors have significant roles in working with members who are negatively affected in emergencies. (See Chapters 6. Contractor and Vendor Agreements and 7. Community Partnerships) Effective health plans emergency interventions can address and protect the narrow margins of members' resilience, health, safety, and independence and prevent the cascading negative emergency effects on typically well-controlled chronic health conditions. This preparation involves mitigating against, rapidly identifying, and reacting to protect members from failure of support systems, including supplies, technologies, and customized environments that usually work in non-emergency times.

Specific roles of care managers and care coordinators must include:

- knowing how to implement the emergency authorization plan for each covered benefit
- developing, implementing, coordinating, and modifying service plans
- assessment, triage, and stratification
- assisting members' with developing, implementing, and updating emergency plans
- life-safety checks and addressing identified needs
- preventing and diverting unnecessary and inappropriate admissions to medical facilities and nursing homes
- advocating and combating healthcare providers' implicit disability biases regarding the quality of life of people with disabilities
- accessing and navigating the complex maze of disaster recovery assistance
- identifying and connecting member needs with community resources





## Assessment, triage, and stratification

Predictive modeling and stratification quickly identify members needing priority assistance by assessing risk factors, developing and refining the triage process based on profile sorts, flagged questions, and type of emergency. Strategies need to be in place to determine which members need to be contacted first in an emergency and how this will be done. Some plans call this predictive modeling.

This predictive modeling integrates emergency risk indicators with screening questions and probes (scripts, dropdown menus, multi-pick options). These questions are used in intake assessments, health risk screenings, annual case management updates, and software programs.

Below is an example of what risk scoring looks like, when appropriate, using zip codes to determine affected members:

**Level 1:** Member is unsafe alone and cannot be alone without assistance; relies on paid and unpaid personal care assistance; does not have family and friends support. Needs assistants who can help and possibly provide transportation in an emergency. Initiate contact immediately

**Level 2:** Member is unsafe alone and cannot be without help; however, has backup helpers willing and able to help in an emergency. Initiate contact within 48 hours

**Level 3:** Member needs help with some activities of daily living (ADL) but is safe at home alone once their ADL needs are met

**Level 4:** Member is safe at home without assistance

(Nuamah & Davis, 2020)

(The Neighborhood Health Dashboard and Inland Empire Health Plan - Using Location Intelligence to Monitor IEHP Members, Providers, and Facilities During Wildfires or Power Outages, 2020)

## Scripts

Valuable tools for staff include scripts (dropdown menus, questions, probes, prompts, multi-pick options) to help ensure consistency when identifying risk factors and developing actionable member emergency plans. These scripts



need to be integrated into service software and other tools. Scripts improve the focus on critical details and help staff avoid less effective and vague planning.

Effective emergency planning must account for the complexity of the situations and thus, clear and simple does not work.

For every complex problem there is an answer that is clear, simple, and wrong.

H.L. Menken

## **Vague versus stronger risk indicators**

Review and revise vague and unclear questions with stronger high-risk characteristic questions and descriptions. The more ambiguous the risk description, the more difficult it is to develop realistic plans.

Vigilance demands peeling the onions, clarifying the layers, and cutting through the rhetoric to activate the laser focus and do the deep dive to create, define and sustain the details.

June Isaacson Kailes

Below are examples of general descriptions that are too vague to be helpful. Following each vague statement is a more specific, concrete, and thus helpful description.

## Table of Examples

### General Descriptions

#### **Weak/Vague**

- is frail
- has multiple complex needs
- has serious respiratory conditions
- has mobility limitations
- has mental health illnesses, alcohol or other drug dependencies

#### **Strong/Detailed**

- needs help in activities of daily living (ADLs), specifically bathing and toileting, dressing, transferring, meal preparation, cleaning
- has significant memory difficulties that prevent performing everyday tasks
- has significant risks based on staff's clinical judgment, specifically \_\_\_\_
- has large gaps in their emergency plans such as
  - depends on dialysis, chemotherapy, or other infusion therapies occurring # times per week or every other day
  - is homeless without stable connections to a homeless shelter
- has serious and persistent mental and behavioral health conditions, specifically \_\_\_\_



## Helpers

### **Weak/Vague**

- lacks support from (relatives, friends, neighbors, others)
- contacts family/friends for support and care as needed
- has a backup plan if the personal attendant or caregiver cannot come or does not show up

### **Strong/Detailed**

- depends on in-home services and personal care assistance (insert #) hours per day, (insert #) days per week. Example: relies on ten (10) or more hours a week of personal attendant or caregiver help and support, spends (insert #) hours of each day with a helper, caregiver
- insert helper list

## Communication

### **Weak/Vague**

- Is comfortable using the internet and email

### **Strong/Detailed**

- in an emergency, member can communicate (when systems are working), by (check all that apply): text, email, landline, helper list contacts, etc. limited or unable to get, use, understand or act on emergency alerts and notifications from televisions, radio stations, or phone
- does not have a cell phone
- does not know how to use the internet effectively
- does not have reliable internet connection



Pedro's disability is quadriplegia due to a hit-and-run driver over five years ago. After hearing about a recent 7 to 10-day power outage in another state, Pedro calls his case manager to discuss his survival concerns if there is an extended power outage where he lives. He asks how he would survive such an event because he uses lots of power-dependent equipment for his independence: a wheelchair, breathing machine, lift to get in and out of bed, a remote front door opener, and a remote gate opener. Pedro is concerned and would like help with planning. He gets 40 hours a week of personal assistance for help with bathing, dressing, transferring, meal preparation, cleaning, eating, etc. However, he does not have an emergency plan or a plan for using alternate power sources to survive.

Member power backup planning involves strengthening the resilience of people who depend on power and battery-dependent life-sustaining and life-supporting equipment such as breathing machines (respirators, ventilators, CPAP, and nebulizers), power wheelchairs and scooters, and oxygen, suction, nutrition, or home dialysis equipment. Monitoring for dependency on life-sustaining impacts is broad. Power-dependent users need clear plans and instructions regarding backup power options. (See Chapter 9. Policy Change and Other Points of Influence: Federal and state regulators) (Kailes, Emergency Power Planning for People Who Use, 2019)

### **Planning for Power Outages**

Note: the following is not displayed in the table format due to accessibility needs regarding table structure.

#### ***Weak/Vague:***

- requires a personal emergency (lifeline) device to manage through the crisis period
- uses equipment needing power
- has a backup plan for this equipment
- can manage without power
- knows the length of time can manage without power
  
- Strong/Detailed:

Is dependent on power for critical, lifesaving, and life-sustaining equipment for breathing, mobility, communication, transferring, health, safety, and independence

Check all equipment(s) member depends on:

- BIPAP
- Biventricular Assist Device (Bivad)
- ESRD at-home dialysis
- electric bed
- enteral feeding tube
- IV infusion pump
- Left Ventricular Assist Device (LVAD)
- motorized wheelchair or scooter
- oxygen concentrator
- Right Ventricular Assist Device (RVAD)
- suction pump
- total artificial heart
- ventilator
- other (specify:\_\_\_)
- home infusion therapies (for daily monitoring)
- connected health devices (telehealth/telemedicine)
- glucose monitors (daily charge)
- temperature-controlled medications
- power adjustable bed
- alternating pressure mattress
- transferring lifts
- rechargeable hearing aids
- sound amplifiers
- speech generating devices (speech output)
- environmental control systems: Smart devices, speakers, and cloud-based services (Alexa, Google Assistant, etc.) for:
  - thermostats, heating/cooling
  - lighting
  - window coverings
  - keyless entry locks



- garage door openers
- pet monitoring and interaction cameras
- Have a way to power or get by without power for EACH piece of equipment; yes or no?
- Able to operate the backup power equipment without help, yes or no?

## Tania's Story

Tania Morales left her home and went to a shelter because she was afraid she'd be trapped at home if the electricity went out. (picture from *Spectrum NEWS*, NY1)



Tania Morales, at a meeting, sitting in her power wheelchair (picture: [www.cidny.org](http://www.cidny.org))

Tania Morales was turned away from the shelter because she was a wheelchair-user. The gate to the ramp, at the shelter, was locked and no one could find the key. Shelter staff sent Tania away in the storm.



Tania using a home power stair chair to get up and down stairs.

## Evacuation and transportation

In 2005, Marcie Roth (currently World Institute on Disability Executive Director) got a call from a New Orleans woman. Benny, a wheelchair user due to quadriplegia, had been unsuccessfully trying to evacuate before

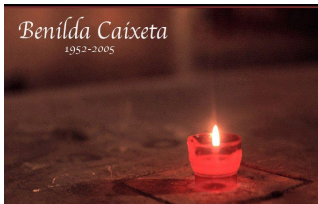


Photo of Benny, smiling, long black hair, wearing a white dress with black polka dots, seated in her wheelchair.

Hurricane Katrina made landfall. She planned to get to the Superdome and needed help. Benny had scheduled trips to evacuate for several days, and each time paratransit never showed up. Finally, the night before Katrina made landfall, Benny called 911 and told them she had chest pains. Still, no one came.

Back in Washington, D.C., Marcie was sure she knew the "right" people who would help! But, after many calls to the "right" people, it was clear Benny would NOT be evacuated. So, Marcie stayed on the phone with Benny most of the day, assuring her that she was doing all she could to ensure help would come.

Benny relied on the same paratransit system that people with disabilities often cannot rely upon, even in good weather. Marcie was on the phone with Benny when she told her in a panicked voice, "the water is rushing in," and then the phone went dead. Five days later, Benny was found in her apartment, dead and floating next to her wheelchair. Benny, along with many others, did not have to drown!



Benilda (Benny) Caixet, 1951-2005



More about Benny's story can be found in the blog, Rooted in Rights: [The Right to Be Rescued](#). Sixteen (16) years later, as Hurricane Ida made landfall, reports were coming into the [Partnership for Inclusive Disaster Strategies](#) hotline from people with disabilities in Louisiana who still have no options or resources to evacuate, forcing them to shelter in place and brace for impact.

## **Evacuation and Transportation**

Note: the following is not displayed in the table format due to accessibility needs regarding table structure.

### ***Weak/Vague***

- can exit home independently
- relies on and knows how to call 911 but has no plan beyond that
- unable to get to safety quickly in case of an emergency
- has difficulty seeking safe shelter
- can get into shelters and other sites ahead of time
- may need help or is unable to get to food, water, supplies, or locations with power

### ***Strong/Detailed***

- can exit home without help/with help, specify each exit
- which exits need power to open and close them (garage door, gate, elevator, etc.)
- can walk to a vehicle
- can be transported with a group in a passenger vehicle, e.g., bus, van, or private automobile
- can leave their geographic area (emergency impact area) without help
- if must leave the area has access to private transportation, specify:  
\_\_\_\_\_
- is unable to travel in a sitting position, needs stretcher transport
- needs to use equipment while being transported, such as oxygen, ventilator, specify: \_\_\_\_\_
- can transfer to a car



- needs assistance transferring to a car
- has a mobility device that can fold or be taken apart and loaded in a trunk or other empty vehicle space
- is eligible for pre-authorized emergency health plan transportation to safely evacuate

Below is an example of needed transportation assistance levels (TALs).

### **Transport levels:**

**TAL 1 – Stretcher:** members who are unable to travel in a sitting position requiring stretcher transport; may require equipment such as oxygen, ventilator or similar. Requires an ambulance or other specialized vehicle for transport depending on circumstance of emergency.

**TAL 2 – Wheelchair:** members who are stable yet have difficulty walking and who risk harm or impairment from wheelchair transport or prolonged periods of sitting. May be transported in a larger group in a wheelchair accessible and appropriate vehicle, e.g., ambulette.

**TAL 3 – Ambulatory:** members who are stable and can walk the distance at a reasonable pace from their home or apartment to a shelter or transportation vehicle. Can be transported in a larger group in a passenger vehicle, e.g., bus, van, or private automobile.

## **Elements of the individual emergency plan**

Emergency planning involves planning for all types of disasters. The negative consequences of hazards, emergencies, and disasters for people with disabilities and others with access and functional needs are typically similar, so planning is critical.

An additional role of the case manager is working with each high-risk member to develop and maintain an “individual emergency plan” as part of the member’s care plan. This individual emergency planning process can be time-consuming and involve several meetings. If this is not an activity that staff can do, consider contracting with community-based organizations that have the time and expertise to work with members to develop their plans. (See Chapter 4. Contractor and Vendor Agreements: CBO contracting opportunities)



It is not sufficient to ask if a member has an emergency plan or if a member knows someone close who knows what to do in case of a natural disaster, disease outbreak, or other wide-scale emergencies. Members' emergency plans should include these ten (10) items at a minimum:

1. Label all equipment with name, phone numbers, email address
2. Document collection (hard copies for a "grab and go" bag) that include:
  - list of equipment, serial numbers, date of delivery, and payors
  - copies of health insurance cards
  - important hard copy information (phone numbers, addresses, prescriptions), in case there is no access to a cell phone or other digital information
  - see personal health information (#8) below
3. Helpers list - how to help identify, communicate with, and maintain a helper list (also called support teams and support network). This list consists of people who agree to help when needed and check on the member in an emergency. Ensure the member has talked with the people on this list and they have agreed to help and how they will help. They must have ways to reach these helpers during and after emergencies
4. Planning for power outages
5. Communications plan – communicating with helpers in an emergency using more than one way: landline phone, cell phone, text, or e-mail. These communication methods can be used from bed and needed chargers should be at the bedside also.

entering helper contacts into cell phone and having hard copies for use on other phones and devices

signing up for local alerts and notifications (text messages and sometimes phone calls and e-mails that provide weather conditions and emergency information)

cautioning members to not depend solely on personal emergency response system (PERS) devices because PERS relies on 911 systems. The 911 call system may not be working or working well due to overwhelming call volumes resulting in long wait times.

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6. Evacuation from home and transportation from area plan

7. Assistance with signing up for local alerts and notifications (text messages and phone calls and e-mails that provide conditions and emergency information)

8. Personal Health Information - Create a hard copy and readily available web-based personal health record (PHR). A PHR is a document where the member maintains important health information. This record provides a summary of critical health information in a secure place. Only the member can allow others to access this data. PHRs can contain a diverse range of data, including but not limited to allergies and adverse drug reactions, chronic condition(s), disability/ies, current medications, surgeries and other procedures, vaccinations, list of equipment, serial numbers and payors, etc.

(Kailes, Emergency Health Information: Savvy Health Care Consumer Series, 2004)

9. Instructions regarding how to

- access medical records if a member needs to see an out-of-network provider when a current provider is not available due to the emergency
- get emergency medications for coverage during an anticipated or actual emergency

10. Emergency supplies and kits

- available medications, emergency supplies, and how to get an emergency supply or early refills for prescriptions, as well as during an emergency
- emergency kits for different places and situations and service animals

Checklist suggests emergency kit contents including no-cost supplies that you can tailor to your needs and abilities. Kits to consider for different places and situations: keep it with you, grab and go, home, bedside, and car. Specific suggestions for hearing, speech and communication, and vision issues and wheelchair and scooter users, service animal owners, and people with allergies, chemical sensitivities, and breathing conditions. (Kailes, Disability Specific Supplies for Emergency Kits, 2016)



## **Connecting members to specific solutions**

Helping members work through their emergency plans includes connecting members to specific solutions and community resources. (See Chapter 5. Member Emergency Communication: Community resources - Help from community organizations)

### **Member rewards**

Use rewards and incentives to motivate members to complete specific parts of their emergency plan, such as a helper list, emergency health information, alternative power plan, and collection of important documents. Rewards could include gift cards, emergency-related gifts such as mylar blankets, phone chargers, flashlights, etc.

### **Life-safety checks and addressing identified needs**

Staff should be prepared to conduct life-safety checks, which involve coordinating with community and government partners to make emergency life-safety contact. And when needed, in-person visits if a member or helper(s) cannot be reached. (See Chapters 6. Contractor and Vendor Agreements: CBO contracting opportunities and 7. Community Partnerships: Roles)

Life-safety checks include reaching out to members, often pre-identified as high-risk, through a triage process (see first section of this chapter above: Assessment, Triage, and Stratification). Check on the members' health, safety and assist with immediate and emerging needs such as:

- replacing critical devices, equipment, supplies, medications
- providing accessible evacuation transportation
- providing personal assistance
- getting health care, remote telehealth monitoring
- use a rapid response emergency services fund for quick expenditures to meet immediate needs and provide nontraditional items such as air conditioner, mold removal, reconstruction of ramps, accessible showers, etc.



- replacing damaged, lost, or left behind: equipment, oxygen, supplies, mobility devices (wheelchairs, canes, crutches, walkers, shower chairs, raised toilet seats), and assistive technology
- delivery of food, water, batteries, chargers, generators, sliding boards, personal protective equipment, prepaid cell phones, mobile device solar chargers, etc.
- member tracking when evacuations result in transport to another area (county or state)
- returning to homes or temporary housing

## **Preventing and diverting unnecessary and inappropriate admissions to medical facilities and institutionalization**

The COVID-19 pandemic made crystal clear the risks of large congregate living settings. Surges in COVID reinforced this learning. More than 40% of all COVID-19 deaths were people with disabilities residing in institutions. The layers of causes of decades-long systemic problems are easy to list:

- overdue staffing reforms
- understaffing
- poor training of staff and volunteers
- backlogs
- suspended inspections and recertifications
- inadequate audits
- poor oversight and enforcement of regulations and more

This Roadmap focuses on preventing and diverting admissions to these settings rather than on all the systemic failures and fixes needed regarding long-term care facilities. These unnecessary deaths and long-standing systemic problems reinforce the critical need for home and community-based services that allow people to stay in their homes. It is easy to admit members to facilities in an emergency, but it is difficult to help them transition back to living in the community. Diversion takes time, effort and pre-planning. Establishing safeguard protocols to divert long-term care facility admissions prevents the standard and repeated default quick fix in emergencies of admitting members to nursing homes. Contracts with community-based organizations serve as an effective means to prevent



institutional admissions and expedite transitions by assisting those who end up in institutions to move back into their homes. (See Chapter 6. Contractor and Vendor Agreements: CBO contracting opportunities)

(Pathways to Community Living, 2021)

(Roads to Freedom Transitions, 2021)

According to the September 2020 Office of Inspector General report, complaints from 2016 to 2018 show that 21 states failed to meet the Centers for Medicare and Medicaid Services timelines for inspecting the second-most serious complaint level. Of those, ten failed to meet the threshold for eight consecutive years from 2011 to 2018. (Downard, 2021)

Like so many others, [Lloyd's Obituary](#) says it all:

On November 16th, after 35 weeks of being imprisoned in a long-term care facility under the pretense of "keeping him safe," Lloyd contracted the very thing they were supposed to be keeping him safe from – facility-acquired COVID-19. He battled through another two weeks of fear, isolation, and illness before his body finally surrendered...This process stole his freedom, his dignity, and his health, but it was unable to steal his beautiful spirit and his handsome smile which he hung on until the very end. As a society, what we have allowed to happen to Lloyd and all those in long term care is despicable. It robs residents and their families of the most fundamental of needs — freedom, love, and affection — and makes the working conditions for their caregivers unbearable. If anyone thinks we are doing the right thing, they have not lived our nightmare of a journey for the past nine months.

And, if you think this doesn't affect you, you are wrong — it just hasn't affected you yet (accessed 7.1.21)

[COVID-19 in Institutions: \(STILL\) Dying in Place; Saving Lives During Emergencies](#) 7/14/21, This virtual event brings together Federal and State Agencies, Centers for Independent Living and people with disabilities to discuss all the aspects of saving lives during emergencies. People with disabilities continue to suffer deep losses and disproportionate death during the COVID-19 Pandemic. Presenters discuss what went wrong; what was done right and most importantly, how to ensure lives are prioritized and saved. (accessed 7.15.21)



## Advocating for members facing potential health care discrimination based on disability

Could Michael's health plan have helped protect his rights and his life?



Michael Hickson in the hospital with his five children, from Melissa Hickson

Michael Hickson, a 46-year-old man with multiple disabilities – quadriplegia, cortical blindness, and anoxic brain injury – experienced a cardiac incident in 2017. He was married; he and his wife had five children. Since becoming disabled in 2017, Mr. Hickson had received ongoing habilitative and medical treatment. Mr. Hickson was an integral and beloved family member whose humor, strength, and personality were demonstrated in myriad ways.

Admitted to St. David's South Austin Medical Center (SDMC) on June 2, 2020, Mr. Hickson was fighting sepsis, a urinary tract infection, and pneumonia. He tested negative for COVID-19 several days before his admission. While seriously ill, these conditions were treatable. SDMC successfully treated him for the same symptoms three months prior. SDMC assessed Mr. Hickson as having a 70% chance of survival.

Antibiotics were initially provided with lab results determining they were effective. Mr. Hickson's physicians even identified the specific bacterial organism at the root of his infection. Yet, they abruptly withdrew the antibiotics and all life-sustaining treatment only three days later, designated Mr. Hickson as Do Not Resuscitate, and placed him in hospice for comfort care. When pressed for an explanation as to why they would not treat him,





Dr. Viet Vo told Mrs. Melissa Hickson in a legally recorded conversation that “as of right now, his quality of life, he doesn’t have much of one.” Dr. Vo compared Mr. Hickson to another of his patients who were being treated aggressively for COVID-19, saying “his quality of life is different than theirs. They were walking, talking.” (OCR Complaint Filed by National Organizations on Behalf of the Family of Michael Hickson, 2020) (Gallegos & Sender, 2021)

The death of Michael Hickson is just one of many examples that raises questions about the impact of disability bias and how that bias leads to discriminatory practices.



Michael Hickson in photo lying in a hospital bed and being kissed by his stepdaughter Mia, from Melissa Hickson

Melissa, his wife says no one asked her husband, Michael, if he wanted to keep getting treatment. “He would say: ‘I want to live. I love my family and my children... that’s the reason for the three years I have fought to survive,’” she says.

(One Man's COVID-19 Death Raises The Worst Fears Of Many People With Disabilities, 2020)

Another example that raises similar questions is the death of Sarah McSweeney. Ms. McSweeney was viewed as vibrant and full of life by those who knew her best. She was a wheelchair-user living in the community who interacted with others with the right supports. Yet, she was deemed by health care providers as having a lower quality of life than individuals who could walk and talk.

(As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?, 2020)

(Examining How Crisis Standard of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients, n.d.)

These are examples of how decisions might be unlawfully made. They illustrate how preparation for these situations could mitigate potential harm. Critical interventions involve advocating for members facing possible triage discrimination and medical bias based on disability or weight, alone or in combination, with other characteristics.

Professional medical associations have guidance on allocation of scarce resources and triage that are inconsistent and utilize criteria inequitable to people with disabilities (such as quality of life, quality life years, life expectancy, or exclusion related to underlying health conditions). However, such guidance has often not included subject matter experts on disability integration, bioethics, and medical/legal crisis standards of care.

The COVID-19 pandemic has magnified this persistent disability discrimination and negative bias in the provision of medical treatment. Although bias can be explicit or implicit, studies have consistently shown that health care providers hold negative views of people with disabilities and tend to apply their own “whole health” perception of the value and quality of life to people with a disability.

Letter to Roger Severino Director, Office for Civil Rights U.S. Department of Health & Human Services, 20201 RE: Complaint of Disability Rights Washington, Self Advocates in Leadership, The Arc of the United States, and Ivanova Smith Against the Washington State Department of Health (WA DOH), the Northwest Healthcare Response Network (NHRN) and the University of Washington Medical Center (UWMC) March 23, 2020 (accessed 11.06.21) [http://thearc.org/wp-content/uploads/2020/03/OCR-Complaint\\_3-23-20.pdf](http://thearc.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20.pdf)

Health care disparities created by the pandemic for people with disabilities are amplified by the utilization of allocation and scarce resource triage models that use stereotyped assumptions about individuals with disabilities.



Examples of categorical triage exclusions for allocation of resources based on disability during COVID-19 (such as intellectual or developmental disability) that raise concern include:

- explicit or implicit quality-of-life assessments
- assumptions regarding long-term survival that disadvantage people with disabilities
- failure to incorporate reasonable modifications in receiving treatment, including allowing for longer time on a ventilator
- provisions authorizing reallocation of ventilators from chronic ventilator users to other patients
- assumptions or concerns about the ability of people with intellectual and developmental disorders to comply with post-treatment protocols; and
- overall failure to require an individual assessment of each patient to avoid decisions based on diagnoses and stereotypes. (COVID-19 and Disability-Based Discrimination in Health Care, 2020)

These resources provide ways to correct these inequities for people with disabilities.

(Know Your Rights Guide to Surviving COVID-19 Triage Protocols, 2020)

(Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability, 2020)

(COVID-19 Advocacy & Resources, 2021)

(Don't deny ventilators to disabled patients, 2020)

## **Navigating Disaster Recovery Assistance**

Assistance in navigating the complex maze of time-consuming disaster recovery is a big job, often needing many layers of disability expertise and advocacy. These intense case management activities can be shared effectively through contracts with disability organizations. These organizations often have the required time and knowledge of disability and disability services. (See Chapter 6. Contractor and Vendor Agreements: CBO contracting opportunities)



In one study, 83% of 42 case managers, and all of their supervisors, agreed that disaster case management for people with disabilities differed from case management with people without disabilities. The participants reported that people with disabilities required qualitatively different case management practices that were more intense, of longer duration, and that included more frequent contacts with the client. Case management needed by clients with disabilities was referred to as

“holistic” or “deep case management” and was used in response to the multiplicity of their service needs. The complexity of these needs required disability expertise

to be able to locate needed supports. As the case management needs were more intensive and time-consuming, fewer cases could then be feasibly managed by each individual case manager, necessitating a smaller caseload. P. 215

... disability expertise was necessary support for negotiating barriers to recovery, as these case managers could interpret, translate, advocate, and understand the needs of the client in a manner that someone without disability-related expertise might not. P. 218 (Disaster Case Management and Individuals with Disabilities, 2010)

## Meaningful measures of success

Employ multiple methods to measure success, such as:

- test and revise, when indicated, member triage and stratification systems
- develop and evaluate for effectiveness scripts for identifying risk factors and for creating actionable member emergency plans
- decrease the number of member emergency plans that only depend on calling 911
- increase the percentage of members who have helper lists as part of their emergency plan
  - entered on mobile phone
  - demonstrated ability to access helper contacts
  - in multiple hard copies
  - in members health plan records



- last update \_\_/\_\_/\_\_ listed
- member has created a grab and go bag

## Chapter Summary

There is much case managers, care coordinators, community health workers, community partners, and contractors can do to protect members before, during, and after emergencies. Health plans can effectively address and protect the narrow margins of members' resilience, health, safety, and independence and prevent the cascading negative emergency effects of typically well-controlled chronic health conditions.

This individual emergency planning process can be time-consuming and involve several meetings. If this is not an activity that staff can do, consider contracting with community-based organizations that have the time and expertise to work with members to develop their plans. (See Chapter 5. Contractor and Vendor Agreements: CBO contracting opportunities)



## Chapter 5: Member Emergency Communication

Posting and disseminating emergency information for members, family members, personal assistants, and caregivers is essential. Clear, concise messages provided before, during, and after an emergency can help members take protective health and safety steps.

### Analyze gaps in emergency content

Information disseminated must be tailored to the needs of members. General emergency preparedness information is relevant for everyone. Health plans can use member data to customize and target some emergency outreach. Emergency preparedness information for the general population, however, is not always enough for people with disabilities. Materials can be more inclusive when they contain information that addresses specific needs, health (hearing, vision, mobility, speech), cognition (thinking, understanding, learning, remembering), and on no-cost and low-cost preparedness strategies. These no-cost preparedness activities include identifying emergency helpers (support people) and developing evacuation plans, collecting emergency health information and emergency documents, discussing these plans with personal attendants and family and significant others, and practicing and updating plans to align with current health and functional needs.

Review member emergency content no less than annually. This review should be done by staff and include member feedback regarding usability, understandability, accuracy, relevance, and gaps.

[Be Real, Specific, and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs](#), Edition 1.0, (2016) Offers advice, examples, and resources on producing and sharing material that has specific functional needs items and includes checking that the content:

- is developed in partnership (for, of, with, and by) people who live with disabilities and others with access and functional needs
- includes specific information for people with limitations in hearing, vision, mobility, speech, and cognition (thinking, understanding, learning, remembering)



- describes disability in accurate and respectful ways and uses neutral terms that avoid offensive words which reflect implicit bias, negative attitudes, and stereotypes
- recognizes that not all people can afford to buy emergency supplies and equipment
- focuses on no-cost and low-cost preparedness in addition to those more costly activities
- is available in clear, accessible, and usable formats and gives users information on how to get these items in other formats such as large print, audio, electronic, or Braille
- uses resources that are clearly described and explained with specific links to more resources (accessed 8.7.21)

## **Standards and building blocks to apply to all channels and content**

Ensuring access to information involves using different ways to offer effective communication. Significant numbers of people can't receive or understand information due to limitations of seeing, hearing, speaking, reading, remembering, understanding, intellectual abilities, and language proficiency. Offering information in useable and understandable formats helps reach people with various abilities, disabilities, ages, reading levels, learning styles, cultures, and native languages. Some people only receive their information orally or visually, and some use alternative formats (Braille, large print, disks, pictures/graphics/symbols, and audio) to access print materials.

[Health Care Rights for People with Disabilities \(2015\)](#) (accessed 7.10.21)

Health plans must provide access to health care services, including preventive care and necessary services. California's Department of Managed Health Care provides this content to help Californians with disabilities understand their rights and get the care they need. Topics include:

[Physical Access to Care](#)

[Communication Assistance - Hearing](#)

[Communication Assistance - Hearing-Deaf](#)

[Communication Assistance - Vision](#)



Regardless of where the message originates, all health plan departments need to follow standards for communication accessibility which use and contribute to the broadest possible understanding of all audiences. These standards are best understood and followed by establishing a messaging process that presents clear, uniform, and operational performance guidance. These standards should detail the who, what, where, when, why, how, save time, prevent poor compliance, inconsistencies, and discriminatory practices. These are building blocks upon which accessibility compliance standards are created and followed by all staff responsible for member emergency communication. Before using the content, health plans should implement a “rapid content standards review” process by trained and experienced people, including member-users with disabilities. Content standards need to include:

### **Clear and plain language content**

Clear and plain content that is more likely to be understood across diverse communities. Avoid or define all abbreviations and acronyms. Translate, explain, or delete content that uses jargon. Jargon is legal speak, health plan speak, emergency-speak, or industry specific language. Examples of clear and plain content instead of jargon are:

- Determining needs instead of psychosocial assessment
- Walk instead of ambulate
- Get worse or worsens instead of exacerbation
- Help connect with services (like transportation, food resources, or assistance in the home) upon returning home from a hospital stay instead of connect with long term services and support

A good practice is to create prewritten messages (pre-tested by users for clarity), ready to be customized, finalized and used per event.

[Rewordify.com](https://www.rewordify.com/) - a free, online tool that simplifies difficult English for better understanding

[plainlanguage.gov](https://www.plainlanguage.gov/) - guidelines that help with writing clearly so readers can:

- find what they need
- understand what they find
- use what they find to meet their needs





[Centers for Disease Control and Prevention \(2014\)](#) Evidence-based tools can help healthcare emergency communications staff create and assess communication products on topics for diverse audiences. Users provide information about seven key communications areas (e.g., main message, behavioral recommendations), and the Index provides an overall score.

Centers for Disease Control and Prevention. (2016). [Everyday Words for Public Health Communication](#)

[National Resource Center on Advancing Emergency Preparedness for Culturally Diverse Communities](#), Drexel University. (2008) focuses on disaster preparedness in culturally diverse communities. Materials include six categories: Community, Type of Emergency, Resource Type, Language, U.S. Region, and those that fall under Multiple Categories

Public Health - Seattle & King County and Northwest Center for Public Health. [Texting for Public Health: Emergency Communication, Health Promotion, and Beyond](#). The toolkit helps plan for and implement text messaging programs for emergencies and more general health promotion. Covers: why text messaging is effective, getting people to subscribe, legal issues, and technological options.

[Language Is More than a Trivial Concern!](#) (2010) gives appropriate terminology to use when speaking with, writing about, or referring to people with disabilities. Challenges readers to be aware of the importance of using disability-neutral terms. Details preferred language and gives reasons for the disability community's preferences. Serves as a reference tool for the public, media, marketers, providers, board members, staff, and volunteers of disability-related organizations. Includes a language quiz and many examples.

### **Reoccurring and reinforcing distribution methods**

Disseminate information using methods which reoccur and reinforce key messages for members. Roll out messages in phases and repeat rollouts to improve reach. Information should be pushed out using multiple channels and repeatedly to reach people who may miss the first or second wave of content.



## ***Distribute information in usable formats***

Make sure that your information is distributed in multiple, usable formats, e.g.,

- large print
- electronic
- audio
- appropriate for non-English speakers
- Braille
- languages
- easy-to-understand pictures in addition to, or instead of, text (information and signs only in print assume people can read, see, and understand the text and the language).

## ***Web pages and social media***

Create policies, guidance, contract language, and training to post website and social media accessible content like captioned videos, videos inclusive of American Sign Language interpreters, long descriptions of graphics, and access to pdf documents. (See Chapter 6. Contractor and Vendor Agreements: CBO contracting opportunities)

Implement a rapid review process to check all content for accessibility before posting and return deficient content to the originating source, along with technical assistance for correcting any problems.

[Competency Planning Checklists for Providing Health Care for People with Disabilities](#) (2016) See section on Communication Access pages 8-14, and Communication access resources pages 19-22.

[Improving the Accessibility of Social Media in Government](#) covers agencies' responsibilities to ensure that digital services are accessible to all people with disabilities. Includes recommendations for improving accessibility of social media, tips for making Facebook posts accessible, Tweets accessible, YouTube videos accessible; and resources, training, and how to provide feedback (2013)



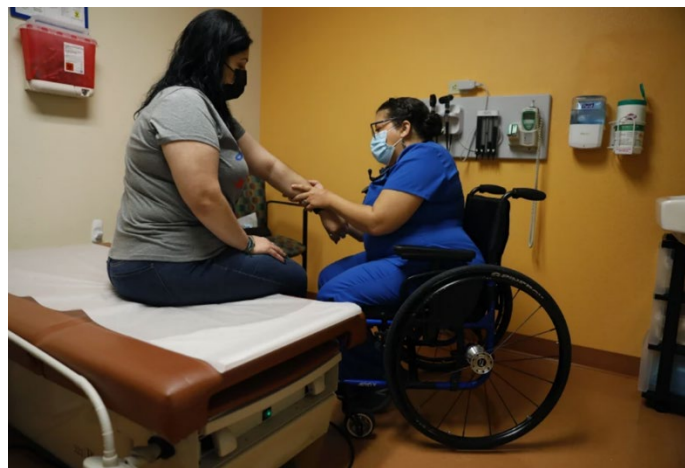
[Section 508 of the Rehabilitation Act](#) requires access to electronic and information technology procured by Federal agencies

The [ICT Testing Baseline for Web Accessibility](#) sets minimum testing criteria and evaluation guidelines to determine if web content meets the 508 Standards that incorporate by reference the Web Content Accessibility Guidelines (WCAG) 2.0 Level A.A. Issued by the W3C's Web Accessibility Initiative, WCAG 2.0 is a globally recognized, technology-neutral standard for web content

[Web Accessibility Initiative \(WAI\)](#) Web provides strategies, guidelines, resources to make the Web accessible to people with disabilities

## ***Depictions***

Implement policies that require pictures of real and diverse people with disabilities in materials. Such depictions portray members who actively participate and are integrated into the community, exercising, working, traveling, shopping, volunteering, playing, and worshipping. This communicates to members and potential members that the health plan attends to nuances of respect and dignity. Care is taken to include real people that reflect members versus using stock photos of models and actors.



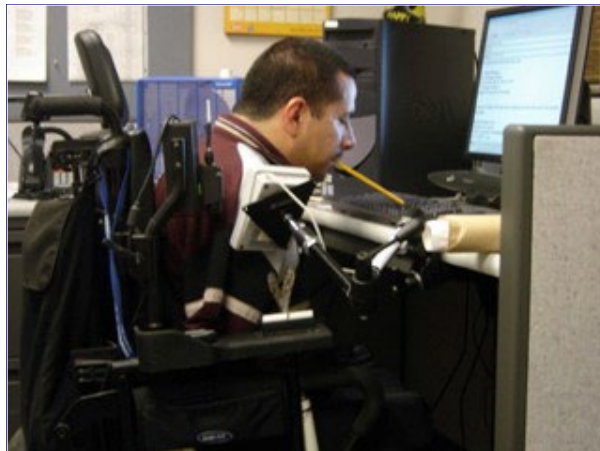
Dr. Marie Flores examines patient Karla Olguin, 35, at the AltaMed clinic in Pico Rivera, California, (Christina House, *Los Angeles Times*)



Woman waving and traveling using a mobility scooter with a suitcase swung over the back of her seat.



Five friends talking and enjoying a picnic, one seated at the head of the table is a wheelchair user drinking a cup of coffee.



Man working at his desk, seated in his power wheelchair, accessing his computer using a mouth stick to type on his keyboard.



Woman using exercise equipment with her mobility scooter parked next to the equipment.



Seven wheelchair users playing basketball.



Four sprinters, one of whom has an above-the-knee prosthesis.

Contrast these “active” pictures with the one below.



A man alone, slouched in a wheelchair, in a dark room, looking depressed and lonely.

Prevent the use of images that reinforce disability biases and stereotypes such as people needing to be cared for, isolated, depressed, unable, using poorly fitted mobility devices, etc. For example, a graphic of an older woman in a wheelchair with a blanket over her lap is an offensive and insulting typical stock image.



One woman in business attire seated in a poorly fitted, much too large wheelchair, shaking hand with another woman seated behind a desk with her laptop open.

Stock photo of a man wearing a blue business suit, smiling while talking on a cell phone, seated in a poorly fitted old style nursing home type of wheelchair.

Models and professional actors without disabilities are offensive also and portray a lack of sincerity and commitment to including real people. Many members can detect models and commercial images of people who clearly do not have disabilities. Avoid using models without disabilities and avoid using models of Black and Indigenous people of color just to “look diverse.”



## Dissemination channels

Dissemination channels need to include multiple methods, such as:

- automated or manual phone calls
- discussion with case managers
- email
- flyers
- newsletters
- new member information and welcome packets
- member handbook
- mailers
- podcasts
- blogs
- posters
- online training modules
- “on hold” out-going telephone messages
- texts
- virtual forums and support groups
- websites and social media
- workshops

Methods should also integrate emergency plans into new and existing wellness programs such as online self-paced instruction and videos, in-person member education classes, work of health plans’ community health workers, and member rewards programs. (See Chapter 4. Case Management, Care Planning and Care Coordination: Member rewards)

During the 2017-2018 emergencies Superior Health Plan® in Texas made 14,000 outbound calls to their members receiving long-term services and supports four to five days before Hurricane Irene made landfall to help members activate their emergency plans. For example, these calls prompted people to complete such tasks as filling prescriptions early and having their grab-and-go bags and evacuation plans ready. Roth, M, Kailes, J.I. & Marshall, M, (2018) [Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters](#)





[Social Media](#): The use and impact of social media platforms (e.g., Twitter, Facebook, LinkedIn, Snapchat, and YouTube) has skyrocketed over the past decade and has significantly supplemented—if not nearly replaced—more traditional means of communication in many areas of the U.S. Recent disasters have highlighted the level to which people use social media to give and get information. (accessed 6.19.21)

Arthur J. Gallagher & Co. (2014). [Social Media and Disaster Communications Checklist](#). This checklist helps emergency planners create a social media plan. It includes steps before, during, and after a disaster and links to social media platform pages.

## Emergency content

Emergency information should include content that covers these three planning, response, and recovery items:

1. Changes in how services are approved, such as removal of quantity restrictions for medications.
2. Emergency help available from the health plan, such as how to:
  - reach the health plan and providers
  - contact your care coordinators
  - contact telehealth services
  - contact the 24-hour nurse line
  - access critical care services like dialysis and chemotherapy, and how to reschedule appointments
  - get or replace consumable supplies, durable medical equipment, and medications
  - get or have delivered food, water, transportation, vaccines
  - get mental health services
  - see a new provider or out-of-network provider when a current provider is not available due to the emergency, for example, primary pharmacy, dialysis centers or chemo and other infusion therapy sites
  - access your medical records
3. How to prepare for emergencies, including information regarding no cost and low-cost planning and supplies, such as how to:



- plan for sheltering-in-place
- plan for ways to power critical mobility devices, life-sustaining, and life-supporting equipment during periods of power loss
- plan with personal care attendants, assistants (consumer-directed and agency-controlled homecare), and helpers
- apply for emergency benefits
- sign up for local alerts and warnings (from fire, police, emergency services, public health)
- sign up for a utility assistance program (specific links that take the user to one particular web page, so they do not get lost in a big general website and give up!)
- pre-apply for disaster food stamps, Supplemental Nutrition Assistance Program (D-SNAP)
- or ask how it may be possible to get an emergency supply or refill prescriptions early

You could reduce people's fears if you gave them some useful information before things went wrong. It's important to create a sense of confidence in the public in their own abilities before a disaster because they're the only ones who are going to be there. No one's going to help you for at least 24 to 72 hours. So, it would be good to know more about it.

Amanda Ripley, well-known author

The resources below are examples of annotated content.

[Be Ready to Go: Evacuation Transportation Planning Tips for People with Access and Functional Needs \(2010\)](#)

[Be Ready to Go: Disability-Specific Supplies for Emergency Kits \(2010\)](#)

[Emergency Evacuation Preparedness: Taking Responsibility for Your Safety, A Guide for People with Disabilities and Other Activity Limitations \(2002\)](#)

- create, review and practice plans
- gather emergency health information
- evaluate need to identify people who will need help during an evacuation



- practice the skill of giving quick information on how to best assist you
- establish personal support networks
- conduct an ability self-assessment
- know your emergency evacuation options

[Emergency Health Information: Savvy Health Care Consumer Series \(2011\)](#)

guides you through developing emergency health information. You should keep copies of this information in your wallet (behind your driver's license or official identification card) and emergency kits. It shares with rescuers important information about you if you are unable to provide information. It contains information about your medications, equipment, allergies, communication needs, preferred treatment, medical providers, and emergency contacts.

[Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical \(2019\)](#) (accessed 7.10.21)

Emergency power planning checklist is for people who use electricity and battery-dependent technology and medical devices, such as:

- breathing machines (respirators, ventilators),
- power wheelchairs and scooters, and
- oxygen, suction, or home dialysis equipment.

Some of this equipment is critical to maintaining independence, while other equipment is vital to keeping members alive! Use this checklist to make power-backup plans, including:

- how to establish a support team
- how to master the skill of giving quick information on how best to help you
- advice from users and
- sources for more information

[Emergency Preparedness for Personal Assistant Services \(PAS\) Users, Edition 2.0, \(2016\)](#) includes:

- tips specific to individuals who use personal assistants, attendants, or caregivers



- a checklist
- “how to” details about support teams, communication, evacuating and sheltering, and supplies.

[Emergency Preparedness: Taking Responsibility for Your Safety - Tips for People with Activity Limitations and Disabilities \(2006\)](#)

[Emergency Supplies Kits for People with Disabilities and Activity Limitations, 2010, Edition 2.0, \(2016\) \(accessed 7.10.21\)](#) Checklist suggests emergency kit contents, including no-cost supplies that you can tailor to your needs and abilities. Kits to consider for different places and situations: keep it with you, grab and go, home, bedside, and car. Specific suggestions for hearing, speech and communication, vision issues, wheelchair and scooter users, service animal owners, and people with allergies, chemical sensitivities, and breathing conditions.

[Out-of-town emergency contacts listed in priority order \(the first person reached calls all others on this list\) \(2015\)](#) Assist in preserving the health and safety of individuals with spinal cord injury in times of uncertainty and upheaval due to natural or human-caused disasters through advanced planning, along with the preparation of professionals and local agencies. Being intellectually and physically equipped for unexpected events can save lives, lessen the emotional impact, and facilitate a quicker adjustment in times of transition

The Inland Empire Health Plan member website is an example of how this information can be used. <https://iehp.org/en/members/helpful-information-and-resources>

## **Community resources - help from community organizations**

Emergency information should help members understand what community emergency resources are available and how to access these services. Some health plans use “Aunt Bertha,” “Unite Us” or similar services, offering members access to online resources that contain “search and connect” functions to services such as local food banks, emergency housing assistance, disaster relief, employment, and more.

Aunt Bertha, A Public Benefit Corporation, is a social service search and referral service in Austin, Texas. The company serves customers across the



United States, ranging from healthcare systems, payors, higher education, housing developments, and more. Links to “Aunt Bertha” vary by state.

[Unite Us - Building Healthier Communities](#) - Creating an efficient system of care within the community to improve health. The only end-to-end solution for social care. Social Determinants. Patient Centered Care. Coordination Software. Software Solutions.

[Healthcare Ready](#) is an interactive map that shows open and closed pharmacies in areas affected by emergencies.

## **Member access to digital tools**

As in the COVID pandemic, access to the Internet and digital tools has been beneficial in many emergencies. For example, the CDC websites provided up-to-date information regarding COVID-19 symptoms, safety steps, and current information about the number of cases, number of deaths, and test positivity rates. The advantages of these tools include protecting one’s safety, health, mental health, and independence. The many benefits include accessing health plan emergency information, scheduling prescription delivery, accessing telehealth services, including video conferencing with doctors, case managers, member educators, community health workers, virtual support groups, videos, health courses, exercise workouts, and community services. Health plans can and did offer innovative practices during the pandemic, which include:

- assistance with acquiring devices and paying for internet connectivity for those unable to afford these items
- technical support to help members use these tools

Promoting and enhancing of members’ digital access should continue as it contributes to telehealth access and communication access in emergencies.

See Mobile Devices for Telehealth/Virtual Care in [Sixth Annual Innovation Award for Medi-Cal Managed Care Health Plans, October 2020, California Department of Health Care Services](#)

[Tips for Emergency Use of Mobile Devices Edition 2, \(2015\)](#) - Cell phones, smartphones, and other mobile wireless devices like tablets are a big part of our lives. We rarely leave home without them, and we often store vital



information on them. In a small or large emergency, they can be a communication lifeline. Provides details regarding preparing your device to quickly get and give emergency information, including a checklist, emergency contacts and documents, alerts, texting, apps, bookmarks of important mobile sites, “no service” backup plans, skill drills, and other resources.

## Meaningful measures of success

Employ multiple methods to measure the success of member emergency communication.

- Seek feedback from users by adding specific questions to online surveys, member satisfaction surveys and facilitated discussions at member advisory group meetings regarding emergency information for usability, understandability, accuracy, relevance, and gaps.

Use social media analytics (time spent on a page, documents downloaded, “likes,” shares, retweets, etc.) (Kailes, Effectively Including People with Disabilities in Policy and Advisory Groups, 2012)

## Chapter Summary

Emergency communication involves posting and disseminating information for members, family members, personal assistants, and caregivers. Clear, concise content and messages provided before, during, and after an emergency helps members take protective health and safety steps. Member emergency communications should:

- analyze gaps in existing emergency content
- set and maintain standards and building blocks to apply to all channels and content
- offer information in useable and understandable formats
- use multiple dissemination channels
- help members get, pay for, and use devices that enable internet connectivity
- employ multiple methods to measure success



## Chapter 6: Contractor and Vendor Agreements

Contractors and vendors include, but are not limited to, health care providers, suppliers of durable medical equipment, consumable medical supplies, transportation, information technology, marketing and social media content, member and provider education and training content, and related materials, clinical and community-based support services.

### Precise contract details increase success

Accessibility and emergency planning, response, and recovery contract obligations must be delineated in all contracts and agreements. These obligations need to be integrated into all procurement processes, including new, renewed, and extended contracts.

Examples of specific contract provisions:

- identify no less than three (3) points of contacts for emergencies (covering 24 hours per day, seven days per week), including cell phones, email, landlines, addresses, etc.
- identify how contract deliverables will differ during an emergency versus during routine business. For example, what is the projected response time, how will the contractor expedite delivery of products and services, how will the contractor expedite responses to requests, and how long will it take to provide emergency direct care or backup workers?
- provide for redundancy in geographic diversity (local, regional and national) to continue service so that more than one of the contractor's locations can supply the needed resources (detail the minimum quantity of a product or availability of additional equipment in an emergency)
- identify any differences in price between routine business product delivery and emergency delivery (hourly rates, fees for expedited service or delivery)
- detail compliance with the Americans with Disabilities Act (ADA) and other disability civil rights laws. Incorporating standard ADA compliance language in the contract assurances section is NOT



sufficient, as many contractors sign these without understanding what these assurances mean.

Boilerplate, non-specific language carries a substantial risk of failure and a substantial risk of discriminatory response. Compliance doesn't happen through boilerplate language but through design and details of processes, procedures, protocols, policies, and training relative to an area of coverage. Accessibility assessments vary significantly with the nature of the service or product. The capacity to comply with contract terms increases substantially with precise compliance details. For example, all videos are open captioned in English and Spanish, member education content includes alternative formats (braille-ready, large print, digital, electronic, audio) and transportation services use wheelchair-accessible vehicles.

- Identify training or exercise requirements to ensure vendors know their roles in emergencies
- Include details of how the performance requirements are met and evaluated regarding the 17 provider and supplier types participating in Medicare and Medicaid programs and detailed in the compliance requirements with the Centers for Medicare & Medicaid Services' Rule.

(Emergency Preparedness Rule, n.d.)

## **Quality contracting improvements**

Every health plan must demonstrate commitment to meeting quality standards and for continuous quality improvement in their contracting. The same is true of their contractors and vendors. Here are examples of what a health plan should do to ensure contracting quality:

- maintain a list of lessons to apply from past contracting mistakes, process problems, adverse events, and promising practices
- develop decision-making tools that guide and justify accessible purchase choices
- research effectiveness of integrating specific emergency performance clauses into the provider, supplier, and contract agreements
- consider incentives such as increased payments for providers who institute model emergency contracting and monitoring practices





## Community-based organizations (CBO) contracting opportunities

Community-based organizations that include known and trusted leadership and staff are often best positioned to reach health plan members in linguistically and culturally appropriate ways. In addition, these organizations should include disability-led organizations who:

- have the disability-lived experience, including knowing the details, diversity, nuances, and complexity of living with a disability firsthand that cannot be duplicated and always thoroughly understood by those without a disability.

What looks vulnerable, fragile, and medically acute to the untrained eye is often just living with disability to people living with disability and those working for and volunteering with embedded disability-led organizations.

- have the skill sets and can apply the deep experience needed to make real the complexities of social determinants of health through systemic advocacy and delivering support services
- have a majority of people with disabilities in leadership and decision-making positions, including the paid staff, volunteers, and board of directors.

CBO contracting opportunities include:

### 1. Developing members' emergency plans with content that is customized and contains:

- information that is relevant to the functional needs of the member with hearing, vision, mobility, speech, behavioral health, and cognition (thinking, understanding, learning, remembering) disabilities.
  - elements such as helper lists, communication plans, evacuation and transportation plans, and alternative power source plan
- no-cost activities
- low-cost supplies (recognizing not all people can afford to buy emergency supplies and equipment)



- other features discussed in (See Chapter 4. Case Management, Care Planning and Care Coordination)
2. Telehealth and telemedicine readiness involving assistance with obtaining, using, and paying for the necessary devices and connectivity (e.g., Smartphones, tablets, speech-generating devices, computers, and Wi-Fi)
  3. Navigating assistance with the complex and lengthy disaster recovery and application processes. This help involves negotiating a service system that often does not accommodate disability-related needs. Barriers include a lack of accessible communications, housing, and transportation. Support for this complicated process requires perseverance and advocacy to help connect individuals with the array of needed resources and ongoing collaboration with other agencies. (See Chapter 4. Case Management, Care Planning and Care Coordination: Navigating disaster recovery assistance)

Disaster survivors with disabilities can experience the same substantive legal issues as any disaster survivor. However, addressing inequitable barriers people with disabilities face in disaster response services, programs, and activities can take a legal professional knowledgeable in disability discrimination as well as how to potentially remedy these barriers and identify how to address unmet needs most efficiently and effectively. (Disaster Case Management and Individuals with Disabilities, 2010)

4. Diversion away from institutions is critical. It is easy to admit members to facilities in an emergency, but difficult to help them transition back to living in the community. Diversion takes time, effort and pre-planning. Establishing safeguard protocols to divert long-term care facility admissions prevents the standard and repeated default quick fix in emergencies of admitting members to nursing homes. How does the health plan coordinate the elements that assist members in avoiding institutionalization? How will a member transition from a residential long-term care facility such as a nursing home or rehabilitation hospital back into the community? (This help is critical after inappropriate placement during and after emergencies.) (See Chapter 4. Case Management, Care Planning and Care Coordination: Preventing and diverting unnecessary and inappropriate admissions to medical facilities and institutionalization)



5. Developing, testing, revising, updating, and disseminating health plan emergency member communications content (See Chapter 5. Member Emergency Communication: Emergency information content), Disseminate emergency communications through:
  - social media (Facebook, Twitter, YouTube, etc.)
  - accessible and reliable websites
  - email lists
  - phone trees
  - pictures in addition to text or voice
  - visual presentation for emergency information given (images in addition to text or voice)
6. Life-safety checks that reach out to members, often pre-identified as high-risk, through a triage process to check on the members' health, safety and assist with immediate and emerging needs (See Chapter 4. Case Management, Care Planning and Care Coordination: Life-Safety Checks and addressing identified needs)
7. Debris removal from blocked sidewalks and accessible paths of travel (not traditionally covered by governmental jurisdictions, contracts that deal with debris not on roads and highways should include sidewalks and curb cuts)
8. Home delivery of food, water, supplies, personal protective equipment (PPE), equipment, etc.
9. Home modifications and repairs

## Chapter Summary

All contractors and vendors need to have their emergency contract obligations clearly delineated. Contracting with community-based organizations is a vital way to augment a health plan's emergency member services.



## Chapter 7: Community Partnerships

The ability for a community to rebound after a disaster is more dependent on the cohesion and sense of interconnectedness that is shared throughout that community, more so than the infrastructure that is in place.

[Resilient Communities – More Than Just “Grit,”](#) Nicolette Louissaint, Tue, May 16, 2017

### Value of participation

Health plans benefit from participation in community emergency-focused partnerships in multiple ways. Members of these partnerships include local community service providers who can complement and assist first responders. Lives saved or lost depend on readiness that typically takes time to mobilize. Thus, community partnerships can maximize effective response, especially in large emergencies when local resources are overwhelmed, and state and federal backup takes significant time to arrive, organize, and respond. In addition, successful collaboration between the private and public sectors helps sustain care during times of crisis and community-wide strain.

### Who are the community partners?

Emergency services are broader than those most often thought of, like emergency management departments or organizations.

Community partners include:

- first responders, law enforcement agencies, fire protection, and emergency medical services
- government, non-government, profit, and non-profit organizations who have, as a primary part of their mission, emergency planning, response, and recovery
- organizations whose roles include mass care, communications, public works, and public health
- planners and managers of mass transit, paratransit, rural transit, community-based organizations, non-governmental organizations, and



private transit operators (taxi, Uber, Lyft, shuttle services, non-emergency medical transportation, etc.)

- state and local departments of:
  - aging
  - airports
  - animals
  - building and safety
  - businesses
  - children's services
  - disability
  - fire
  - health
  - healthcare coalitions
  - housing
  - information technology providers
  - mental health
  - parks and recreation
  - police and law enforcement
  - procurement and contracting
  - public health
  - libraries
  - transportation
  - utilities

Community service organizations whose missions are not generally directed at emergency response can and do play critical roles in supporting people with disabilities and others with access and functional needs.

Wide membership from organizations "for, of, by and with" people with disabilities as well as those representing diverse disability organizations and advocates include, but are not limited to:

- disability-led organizations ("for, of, by, and with") such as centers for independent living
- assistive technology programs



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. This system makes assistive technology devices and services more available and accessible to individuals with disabilities and their families. Each state, the District of Columbia, Puerto Rico, and the territories (American Samoa, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands) each gets one grant.

- organizations serving specific disability groups such as individuals with multiple sclerosis or intellectual disabilities
- public and private personal care services or fiscal agents of personal assistance
- aging and disability resource centers
- durable medical equipment vendors
- community health clinics and federally qualified health centers
- faith-based organizations
- food banks and suppliers of free meals
- legal assistance organizations
- organizations that have emergency services as their primary mission:
  - Voluntary Organizations Active in Disasters
  - American Red Cross
  - Community Emergency Response Teams (CERT)
- Healthcare Coalitions
- long-term recovery groups and committees

## **Healthcare Coalitions**

Many people do not know about Healthcare Coalitions (HCCs). HCCs are groups of individual healthcare and response organizations in a defined geographic location that serve as a multi-agency coordinating group, supporting and integrating work with public health and medical services activities. HCC member composition varies by jurisdiction but should include hospitals, emergency medical services (EMS), emergency management organizations, and public health agencies. Other partners may consist of behavioral health, long-term care, pharmacies, tribal entities, public safety, and many community-based and non-governmental organizations. HCCs are



funded through the Hospital Preparedness Program, first piloted in 2007 and continuously funded nationwide since 2012.

HCCs' primary functions include information dissemination, information gathering, reporting, and logistical support. In addition, HCCs have roles during preparedness and response. HCCs serve as communication hubs for participating entities and coordinate sharing resources, policies, and practices before and during an event.

The Office of the Assistant Secretary for Preparedness and Response (ASPR), within the United States Department of Health and Human Services, oversees HCCs. ASPR always should expand HCC membership and scope to include health plans and community-based organizations. In addition, the Hospital Preparedness Program should redefine the HCCs' role to include vital coordination, collaboration, and cooperation functions with a broader group of community-based organizations and others who do and will play roles in emergency planning, response, and recovery. (The Healthcare Coalition Overview, 2012)

## Roles

Community partnership roles can include:

- supporting members' preparedness and response efforts through coordination, collaboration, consultation, and communication
- member coordination of roles to prevent unnecessary duplication
- building and depending on relationships through establishing and maintaining active connections with community partners in planning, exercises, drills, response, and recovery activities
- problem-solving and organizing resources to meet urgent needs and anticipate overcoming geographical and logistical challenges to provide notification, actionable instructions, evacuation, rescue, accessible transportation, sheltering, and health care
- maximizing quick responses versus slow, lagging disorganized response
- establishing contracts with community-based organizations (See Chapter 6. Contractor and Vendor Agreements: CBO contracting opportunities)



- organizing delivery of needed items that are damaged, destroyed, lost, or left behind, such as delivery of food, water, generators, fuel, equipment, supplies, medication, mobility devices (wheelchairs, canes, walkers, shower chairs, raised toilet seats), air conditioners and air filters, and communication devices
- providing services such as:
  - disaster case management to navigate disaster benefit programs
  - mold removal
  - reconstruction of ramps, accessible showers
  - loaned equipment
  - transportation for food, health care appointments, and repair shopping
- helping individuals with transitions back home or to temporary and new homes through exercising flexibility in the funding of non-traditional services
- asking and processing the challenging questions such as:
  - Do community partners have a process in place to contact people? If yes, how are these procedures kept current and tested?
  - How will they deal with insufficient sign language interpreters in the area?
  - How can partners help deliver trusted emergency messages to the people they support or serve and identify usable wheelchair-accessible emergency transportation and evacuation resources?
- coordinating and sharing the work of life-safety checks by leveraging partnerships with organizations that maintain current lists of those who will be most negatively and disproportionately affected and need lifesaving, life-sustaining, and life-supporting assistance.

## Emergency coordinating examples

During 2017-2019 emergencies, Anthem quickly contracted with Portlight Strategies and the [Partnership for Inclusive Disaster Strategies](#) (Partnership) to facilitate projects involving disaster relief for people with disabilities. Anthem wanted to increase the effectiveness of its member outreach services. This partnership relies on:





1. trusting relationships built over several years. This agreement paired Anthem's health care expertise with the Partnership's disaster response competencies, deep understanding of the complexities and nuances of the lived disability experience to create an effective collaboration.
2. current and strong connections to other local and self-organized responders, such as the Cajun Navy, helped Anthem respond more quickly and support people in their communities during the hurricanes Harvey, Irma, and Maria.

Rapidly augmenting Anthem's response with Portlight and the Partnership's expertise just made good sense, enlisting experienced responders and local community engagement experts with the know-how, creativity, nimbleness, and flexibility to help our members get immediate critical needs met.

Merrill A. Friedman, Senior Director, Disability Policy Engagement, Federal Affairs, Anthem, Inc.

Sunshine Health® is working to strengthen partnerships with Centers for Independent Living (CILs). For example, they are piloting an approach with the Miami Center for Independent Living serving the same Medicaid population, sharing capacity to co-manage information during disasters and provide updated information via automated outbound calls. Sunshine Health® is also partnering with Florida's Association of Centers for Independent Living to determine each Center's capacity to provide emergency preparedness and disaster response services. (Roth, Kailes, & Marshal J.D., 2018)

During Hurricane Florence, the North Carolina Emergency Management (NCEM) Disability Integration Specialist convened the NCEM CMIST (Communication, Maintaining Health, Independence, Safety, Support, and Self Determination, and Transportation) Advisory Committee and quickly expanded by inviting other organizations. This NCEM Disability Stakeholders group began organizing conference calls on September 12, two days before landfall, and these calls continued daily through September 28, 2018.

The Disability Emergency Briefing Team, responding to the 2007 California wildfires, is an early example of effective collaboration between government and community-based organizations. This team, meeting by conference calls, consisted primarily of staff from the:



- California Foundation for Independent Living Centers Access to Readiness Coalition
- Alliance for Technology Access Assistive Technology Network
- Disability Rights Advocates
- Protection and Advocacy Inc.
- Access to Independence, San Diego
- Rolling Start Inc. San Bernardino
- Public Authority of San Bernardino County, In-Home Support Services
- County of San Diego In-Home Support Services Public Authority
- FEMA's National Disability Coordinator (responsible for integrating disability issues into federal emergency planning and preparedness efforts)

The content of daily calls identified where and what individuals had essential unmet needs. This group helped to mobilize and facilitate a response from local disability service community providers. These calls focused on problem-solving critical unmet needs, ranging from replacing a service animal's dog harness to replacing left-behind, lost, or damaged supplies and equipment. (Wheelchairs, canes, walkers, shower chairs, raised toilet seats, etc.) (Kailes, Southern California Wildfire After Action Report, 2008)

[Addressing Social Needs Amid the COVID-19 Pandemic: A Survey of Dual Eligible Special Needs Plans - CHCS Blog](#), Center for Health Care Strategies, January 27, 2021

The [Mayor's Office for People with Disabilities Disaster Resilience Resource Network](#)

[Guidance for Integrating People with Disabilities in Emergency Drills and Exercises](#)

[A Ladder of Citizen Participation](#), Sherry R. Arnstein, 1969

## Meaningful measures of success

It is vital to employ multiple evaluation methods to measure the success of community partnerships. Gathering data about services and equipment provided, the efficiency of operations calculated in time are all possible measures of success. For example,



- Twelve-member (12) community partners organizations successfully tested and strengthened their emergency communication network. This network tested each organizations' methods to quickly broadcast emergency messages through their channels which included: calls, social media, texts, and email lists. As a result, this community network determined it could quickly message over 800,000 people with disabilities and others with access and functional needs.
- In 2020, the Disability Disaster Access and Resources (DDAR) program of the California Foundation for Independent Living Centers (CFILC) provided services to over 2,500 people with disabilities and older adults. These individuals utilize electricity-powered devices and technology to meet living, safety, and independence needs. This partnership between the utility company, Pacific Gas & Electric, CFILC, and its network of Centers for Independent Living (led by, for, and with people with disabilities) provided power-dependent individuals affected by Public Safety Power Shutoffs with:
  - Batteries provided - 1125
  - Hotel nights - 537
  - Transportation or gas – 63
  - Meals and food resources – 985
  - Individuals assisted in signing up for the Pacific Gas & Electric's Medical Baseline program -1,231 (Power Outages Fact Sheet, n.d.)

## Chapter Summary

Health plans benefit from community emergency partnerships to maximize effective planning and response, especially in large emergencies when local government resources are overwhelmed and state and federal backup takes significant time to arrive, organize, and respond. The benefits include:

- maintaining active connections with community partners in planning, exercises, drills, response, and recovery activities
- organizing delivery of needed items
- coordinating life-safety checks by leveraging partnerships with organizations that maintain current lists of those who will be the most



negatively and disproportionately impacted and need lifesaving, life-sustaining, and life-supporting assistance.



## Chapter 8: Workforce Training

The one-and-done training model doesn't work. Time and budgets for training are minuscule. It is vital to invest in training to prevent getting stuck in outdated learning and evaluation methods.

In the emergency management world, applying lessons learned from prior mistakes can make the difference between life and death for people with disabilities and others with access and functional needs. It's about impact and outcomes. The goal is not just lessons observed, documented, or heard about, but lessons repeatedly applied, so we can eventually claim them as lessons learned.

A cross-functional management planning and response team (See Chapter 3. Leadership) needs to reinforce emergency workforce training. The team should be inclusive of all departments that touch the member. Effective training sharpens performance while increasing skills, giving permission to and showing employees how to problem-solve quickly during an emergency. Mentoring and providing feedback to employees is a crucial piece to this learning.

It also includes refreshing content and materials frequently, training teams, emphasizing participatory exercises, spacing learning in intervals, valuing and using just-in-time training, and measuring performance, impact, and outcomes.

It is vital to prevent investment in developing training from getting stuck in outdated learning and evaluation models.

### **Refresh content and materials frequently**

Old, standardized training models have not adapted to reduced reading levels and shortened attention spans for all age groups (partially due to the growing intensity of our "screen sucking" world of tablets, smartphones, game consoles, television, and streaming). As a result, the quality of training content quickly degrades, and learners easily forget what they were supposed to have learned. In addition, systems that lack the flexibility and agility to refresh training material continually and produce meaningful "real-time" types of exercises result in stale, inaccurate, and potentially damaging content and skills not learned.



## Training teams

Training teams can work together to identify and apply new tactics and methods, leading to improved performance. In addition, teams are often more successful than individuals in working around competing priorities, heavy workloads, and lack of leadership support to convert lessons observed into practice and improved performance. Health plan teams also benefit from learning collaboratives to share good practices, apply quality improvement methods, and solve problems.

## Elevate the importance of exercises

Getting learners to work on solving problems before they learn about the solutions leads to better learning. Individuals learn best when they struggle creatively with the material, both old and new. Functional emergency exercises that focus on specific scenarios can give learners indelible memories and frames of reference and increase motivation to improve planning, practice, and performance.

## Spaced reinforced interval learning

Resilient, hard-wired learning occurs over time, not in one-time only webinars or one or two-day training. Effective inclusion of new practices often takes multiple exposures to the material. Quality training includes repeated connection with learners using hybrid and blended training modes: in-person, online, conference calls, webinars, and learning collaboratives. Shorter and spaced learning contacts provide learners time to analyze, synthesize and apply new competencies!

Reinforce and integrate emergency content through multiple exposure methods such as

- via the organization's intranet or staff portal "just in time" - easy to find information, resources, checklists, processes, procedures, protocols, and policies
- staff know who they can call for emergency-related technical support
- onboarding and new staff orientation
- integrating content during staff meetings, making more teachable moments during meeting time



- scheduling regular discussion groups that focus on problem-solving
- participation in emergency local exercises
- learning collaboratives or “communities of practice”
- workshops
  - in person
  - short webinars (includes access to archived content)
  - short online training modules and self-study options
  - videos
  - podcasts

(Kailes, Guidance for Integrating People with Disabilities in Emergency Drills and Exercises, Edition 2, 2020)

### **Put greater emphasis on just-in-time training**

Greater or at least equal attention to just-in-time training should be the standard when creating and revising emergency training. Just-in-time training addresses the reality that the people trained yesterday won't be there tomorrow! In addition, people “can't remember stuff” (CSR) on a good day. They remember even less during high-stress, chaotic emergencies. Achieving “muscle memory” as people do in regular exercise regimes would be nice but is not realistic, given the periodic occurrences of emergencies and the staff turnover rate.

Staff need help to untangle and connect information from dangling threads coming from multiple departments. Wading through plans, processes, procedures, protocols, policies, and training notes to get to the critical steps is tough, and few people have the available time or patience to do this. The essence of real, actionable, practical, usable, tactical, and deployable steps needs to be available in scripts, checklists, guides, and job aids that sustain and reinforce the competencies. The player's bench is constantly changing, but all need a concise, standard playbook.

Information that is easy to access on the organizations' intranet or staff portal for quick review is vital for refreshers and first-time exposure to information. There's nothing like captive and hungry learners to turbocharge the learning curve. So, pay equal attention to just-in-time training tools.

For example:



- using scripts for staff doing assessments, working with members on emergency planning, and conducting life-safety checks improves coverage of critical details (See Chapter 4. Case Management, Care Planning and Care Coordination: Assessment, triage, stratification, and members' emergency plan, life-safety checks)
- establishing call center emergency protocols, including just-in-time training and scripts. In addition, provide staff answering calls during emergencies with content and directions on how and when to escalate callers through warm internal hand-off connections for those needing immediate critical assistance
  - warm hand-offs (making an introduction in person with the member to whom the member is being referred, including remaining on a three-way phone call until the right connection is made) are especially vital when local first responders and the government's 911, 211, and 311 call centers are not functioning well due to overwhelming call volumes, long wait times, or who may not have the needed answers to the questions
- applying Health Insurance Portability and Accountability Act (HIPAA) Privacy Rules in emergencies (HIPAA Disclosures in Emergency Situations, n.d.)
- integrating communication accessibility and telehealth reminders such as facial audio accessibility, descriptive narration (narrating visual content for low vision and no vision members), incorporating sign language and language interpreters, and captioning
- resorting to "old school" contingency plans during widespread and prolonged power outages (hard copy plans, in-person visits, runners, etc.)
- ensuring that annual "mandatory" training required in many healthcare settings includes new information and requires interaction with updated materials

The volume and complexity of what we know has exceeded our individual ability to deliver its benefits correctly, safely, or reliably...Checklists seem able to defend anyone, even the experienced, against failure in many more





tasks than we realized...Under conditions of complexity, not only are checklists some help, but they are also required for success.

Antul Gawande, *The Checklist Manifesto: How to Get Things Right*

### **Use evaluation methods that measure performance, impact, and outcomes**

Use evaluation methods that measure performance, impact on members, and results rather than just rating the process such as: how many attended, how many answered so many post-test questions correctly, and the learners' reactions to and satisfaction with the training and presenters.

The gold standard should be metrics related to performance. Were targeted outcomes achieved? In addition to self-reports, use independent evaluators to analyze targeted results and the raw, uncensored post-event evaluation discussions.

Lastly, debrief everything! Training methods and outcomes only get better when the feedback gathered improves the training content and methods. Therefore, after each training, devote time to analyzing what worked, what didn't work, and what needs work. Then make the necessary changes to improve the training. (Brown, Roediger, & McDaniel, 2014)

## **Chapter Summary**

Workforce training can change behaviors and increase skills, giving permission to and showing employees how to think on their feet during an emergency. Mentoring and providing feedback to employees is a crucial piece to this learning. Emergency training should include:

- refreshing content and materials frequently
- training teams (not just individuals)
- elevating the importance of exercises
- spaced and reinforced interval learning (not one and done)
- placing greater or at least equal emphasis on just-in-time training
- using evaluation methods that measure performance, impact, and outcomes
- always seeking more feedback to improve both content and outcomes



Greater (or at the least equal) attention to just-in-time training should be the standard when creating and revising emergency training. Just-in-time training addresses the reality that the people trained yesterday won't be there tomorrow! In addition, people "can't remember stuff" (CRS) on a good day. They remember even less during high-stress, chaotic emergencies. Achieving muscle memory as people do in regular exercise regimes would be nice but not realistic, given the periodic occurrences of emergencies and the staff turnover rate.

## Chapter 9: Policy Change and Other Points of Influence

What we've seen during the pandemic is the State goes silent about matters like this (emergency roles), implying that we are still expected to meet all these requirements. Because we're so overloaded with duties, it's impossible to fulfill those AND shift our focus to respond to the emergency. We are also hearing now that we are expected to be back at the pre-pandemic baseline for basically everything NOW, even though the pandemic isn't remotely over. If the regulators continue to do this – discount how long emergencies go on for and their aftereffects – we really can't address the issues properly long-term.

If the State would include emergency planning in the costs that are considered for rate setting, that would help. Or they could make a separate pot of money available. But in the Medi-Caid plan space, any time you want to do something new, we always get asked where the additional funding is coming from. As staff, we are absolutely at capacity of what requirements we can take on without hiring new people. And our funding for new positions must come from somewhere.

Anonymous

### Change Agents

Expectations without policy, training and guidance yield unsatisfactory results. There must be regulatory and statutory support from the state and federal government to accelerate and increase the adoption of member-focused emergency health plan practices detailed in this Roadmap. In addition to government support, other organizations and entities can use their influence to drive change that fosters these emergency interventions.

Organizations and entities who are or can be those influencers and change agents who move the needle toward increasing effective member-focused emergency practices include:

- accrediting organizations, standard-setting bodies, and quality assurance organizations
- disability-focused organizations
- disability-led organizations



- grant makers
- professional health organizations and trade associations

Examples of potential change agents include, but are not limited to, these groupings of specific organizations.

### **Accrediting organizations, standard-setting bodies, and quality assurance organizations**

- Agency for Healthcare Research and Quality (AHRQ)
- Healthcare Effectiveness Data and Information Set (HEDIS)
- National Committee for Quality Assurance (NCQA)
- National Quality Forum (NQF)
- Long Term Quality Alliance
- The Joint Commission
- Utilization Review Accreditation Commission [URAC]

### **Disability-focused organizations**

- United Spinal Association
- Paralyzed Veterans Association
- The ARC

### **Disability-led organizations**

- Association of Programs for Rural Independent Living (APRIL)
- Autistic Self Advocacy Network (ASAN)
- National Council on Independent Living (NCIL)
- Partnership for Inclusive Disaster Strategies (Partnership)

### **Federal and state agencies**

- Administration for Community Living (ACL), a department within the US Department of Health and Human Services



- The Assistant Secretary for Planning and Evaluation is the principal advisor to the Secretary of the U.S. Department of Health and Human Services (ASPR)
- Centers for Medicare and Medicaid Services (CMS)

## **Grant makers**

### **Professional health organizations and trade associations**

- AARP Public Policy Institute
- Academy Health
- Advancing States
- American Association on Health and Disability
- American Association of Public Health (APHA)
- American Congress of Rehabilitation of Medicine (ACRM)
- American Health Care Association / National Center for Assisted Living (AHCA/NCAL)
- America's Health Insurance Plans (AHIP)
- Association of University Centers on Disabilities (AUCD)
- Healthcare Coalitions (HCCs)
- Health Plan Associations
- National Association of Area Agencies on Aging (n4a)
- National Association of County Behavioral Health and Developmental Disability Directors
- National Association of Medicaid Directors
- National Pace Association
- National Quality Forum
- Medicaid Health Plans of America (MHPA)
- Medicaid Managed Care Congress
- National MLTSS Health Plan Association
- Partnership for Medicaid Based Home Care
- Special Needs Plans Alliance (SNP)

## **Researchers**

- Center for Health Care Strategies



- Kaiser Family Foundation
- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDRR)
- National Institutes of Health (NIH)

## Policy change opportunities

Sections of this Roadmap offer specific details regarding member-centered emergency practices. Below are entities that can work toward implementation of these recommendations:

- state and federal regulators
- contracts with vendors and providers who supply lifesaving, supporting, and sustaining therapies, equipment, and supplies
- developers of audit standards
- grant makers
- researchers
- developers of industry-wide health plan guidance

### State contracts

State contracts with health plans, for example, should require detailed practices.

Below are two examples of vague state contract requirements that would benefit from specific details to strengthen them.

- The state requires that Medicaid health plans have a well-documented emergency plan in place for specific members.

**Problem:** There is no mention of definitions for “well documented” “specific members” or that plans should be reviewed and updated no less than annually.

The Care Manager shall counsel a Member who resides in a community setting about the importance of developing a disaster/emergency plan for the Member’s household that considers the special needs of the Member. The Care Manager shall encourage the Member to register with the State’s Emergency



Preparedness Voluntary Registry. The Care Manager shall assist the Member to complete the registration process.

**Problem:** these requirements shift responsibility to other agencies and rely on unproven and unsuccessful registry response methods.

The problems described above can be strengthened by defining specific members as those with high-risk characteristics including but not limited to:

- needs help in activities of daily living (ADLs) such as bathing and toileting, dressing, transferring, meal preparation, routine cleaning, etc.
- has significant memory difficulties
- has substantial gaps in their emergency plans
- depends on dialysis, chemotherapy, or other infusion therapies occurring (insert # \_\_) times per week or every other day
- has severe and persistent mental and behavioral health conditions, specifically (insert \_\_) relies on ten (10) or more hours a week of personal attendant, caregiver help, support assistance, spends (insert # \_\_) hours of each day with a helper or caregiver
- limited or unable to get, use, understand or act on emergency alerts and notifications from televisions, radio stations, or phone
- does not have a cell phone
- unable to connect to or use the internet effectively
- is dependent on power for critical, lifesaving, and life-sustaining equipment for mobility, communication, transferring, breathing, health, safety, and independence

(See Chapter 4. Case Management, Care Planning and Care Coordination: Vague versus stronger risk indicators)

Defining what a well-documented member emergency plan should:

- develop a list of helpers and their emergency contact information
- communication plan
- plan for power outages



- plan for evacuation from home and area using accessible transportation
- plan for emergency supplies and how to get refills for prescriptions in an emergency
- create emergency kits for different places and situations, e.g., 1) keep it with you, 2) grab and go, 3) home, 4) bedside, and 5) vehicle.

(See Chapter 4. Case Management, Care Planning and Care Coordination: Elements of the individual emergency plan)

Do not rely on unproven and unsuccessful registry methods of response. Based on the documented experiences of the 2017 and 2018 disasters and previous emergencies, most, if not all, access and functional needs registries have common system problems.

A registry plan may sound feasible, but it may not achieve its well-intentioned objectives for two significant reasons. First, the response capacity is not considered or calculated based on the size of potential events, and second, knowing where people live doesn't tell you where they are at the time of the event. The former presumes that there are enough responders available for mid-to large-scale events when there are not. The latter waste critical resources and time as responders look for people in the wrong places, helping neither the responder nor the evacuee. The below resource discusses some alternatives to registries.

[Emergency Registries](#) – some view registries as an easy and logical answer for addressing what is perceived as “special needs” for a small population segment. Registry issues are complex, and the needs of people, when functionally defined, are not special and are not limited to just a small group of people. Contains:

- [flowchart and assessment tool](#) for making decisions about using a registry
- Defines [what registries are](#), and the types of registries used in emergency management
- [research](#) - existing and needed
- [papers, presentations, and archived webinars](#)





Broaden emergency waivers and flexibilities to enable quick delivery of vital care and services such as the delivery of emergency caregivers, medications, food, supplies, transportation, equipment for alternative power, etc. (See Chapter 3. Leadership: Roles of an Emergency Oversight Team)

Build data-sharing platforms (also known as Health Information Exchanges) with hospitals and health clinics to ensure plans immediately receive notice and data on member hospital admissions, emergency department visits, and pending discharges. Such notification and data allow health plan staff to assist with the transition to community living and prevent institutionalization.

### **Federal and state regulators**

Federal and state regulators should develop regulatory requirements for vendors and providers who supply lifesaving, supporting, and sustaining therapies, equipment, and supplies (upon delivery, service, and repair) to instruct members on activating emergency procedures for the equipment or service. These instructions include alternative ways to safely power the equipment with clear verbal, online documents, hard copy (including pictures) directions in usable and understandable formats and preferred languages. For example:

- information regarding how long batteries and backup systems will last and how to extend use with limited or no power
- dialysis and other critical infusion therapy providers must give members detailed emergency instructions that include what to do when provider sites become unavailable due to the emergency
- vendors and providers must conduct annual reviews to assess and update the accuracy and effectiveness of these instructions (clarity, practicality, plain, understandable, and culturally appropriate). (See Chapter 6. Contractor and Vendor Agreements: Boilerplate, non-specific language carries a risk of failure)

Federal and state regulators should encourage innovation and meaningful metrics:



Innovations include rewarding emergency efforts related to quality improvement projects, rewards and incentive programs, pay-for-performance programs. For example, use rewards and incentives to:

- motivate members to complete specific parts of their emergency plan (See Chapter 4. Case Management, Care Planning and Care Coordination: Member rewards)
- encourage health plans to help members get, pay for, and use devices that enable internet connectivity and access to telehealth services (See Chapter 5. Member Emergency Communication: Members access to digital tools)
- create and integrate emergency planning content into new and existing wellness programs such as online self-paced instruction and videos, in-person member education classes, and the work of health plans' community health workers (See Chapter 5. Member Emergency Communication: Dissemination channels)

(Mental health app now available to members at no cost, 2020)

Paying Medi-Cal Managed Care Plans for Value: Design Recommendations for a Quality Incentive Program (Zayhowski, Jennifer N. Sayles, & Bailit, 2021)

Development of meaningful metrics includes promoting and funding research organizations, including contractors and graduate students. The research contributes to quality improvement by studying and testing for evidence of effectiveness and impact of emergency member-centered interventions. This research includes:

- creating performance competency measures, success indicators, and standards
- examining proof of activation of agreed-upon practices in emergencies
- integration of emergency interventions into health equity, social determinants of health, in lieu of services, population health, and quality improvement projects
- determining which script questions used by case managers (See Chapter 4. Case Management, Care Planning and Care Coordination:



Scripts) yield the best results in determining member emergency risk factors and developing actionable member emergency plans

- documenting evidence regarding if and how emergency practices led to decreased mortality rates, better member health, resiliency, and cost savings
- determining if results from feedback questions were integrated into member advisory group discussions and if member satisfaction survey results are integrated into future practices
- determining if lessons documented in post-emergency evaluations are applied in subsequent emergencies
- outcome results from:
  - member communication methods
  - rewards and incentive programs and pay-for-performance programs
  - integrating specific emergency performance clauses into the provider, supplier, and contract agreements (See Chapter 6. Contractor and Vendor Agreements: Examples of specific contract provisions)
- contracting with community-based organizations (See Chapter 6. Contractor and Vendor Agreements: Contracting with community-based organizations)

#### Blue Shield of California (Promise Health Plan)

##### The Neighborhood Health Dashboard

Blue Shield of California partnered with my Sidewalk, a data intelligence platform, to equip users with information on communities. The Neighborhood Health Dashboard allows all Californians to create health reports on community strengths and needs.

To be truly data-driven, it is essential to tell a story about progress in communities. Establishing a baseline lays the groundwork for tracking and reporting but often requires resources. This data is often publicly available yet costly to align with other data sets. Even for those that have established infrastructure, it takes time to produce a single report, or a community health needs assessment.

We need to standardize this process to communicate the value proposition of public health. With access to these indicators, resources can be spent on



ensuring community input is paving the way. By democratizing the data, the Neighborhood Health Dashboard can defragment the needs assessments – ensuring funding goes where it is needed and makes progress towards health equity. (Sixth Annual Innovation Award for Medi-Cal Managed Care Health Plans, 2020)

### **Additional recommended health plan requirements**

Many organizations can use their influence and funds to drive change. This influence goes beyond what state contracts and regulations can do to affect change. Minimum and uniform effective and sustained member-centered emergency practice interventions are a multi-prong and multi-level responsibility. Below are additional examples of specific and detailed requirements health plans should include.

#### ***Health plan leadership should:***

Create an emergency cross-functional management planning and response team with the time, resources, authority, and responsibility to implement and sustain change efforts across departments, such as:

- work to ensure inter-operability and comparability of software programs to share member information and strengthen a coordinated response across health plan departments to connect the threads of the many departments that touch members
- creating feedback loops for staff that are easy to use and produce valuable information for current and future quality improvement efforts, e.g., devoting adequate time to feedback sessions during and after emergency practice implementation, training, exercises, and opportunities to discuss and plan for how new lessons will be applied.

(See Chapter 3. Leadership: Roles of an Emergency Oversight Team)

#### ***Case management, care planning, and care coordination department should:***

- identify who will be the most negatively and disproportionately affected and need lifesaving, life-sustaining, and life-supporting assistance



- create and use an assessment, triage, stratification system, and members' emergency plans to determine which members need to be contacted first in an emergency and use scripts to help ensure consistency when identifying risk factors
- conduct life-safety checks to address critical needs
- work to prevent and divert admissions to medical facilities and institutionalizations
- connect members with needed community resources
- provide follow along assistance in accessing and navigating the complex maze of disaster recovery assistance

(See Chapter 4. Case Management, Care Planning and Care Coordination)

***Member emergency communication should include:***

- posting and disseminating information for members, family members, personal assistance, and caregivers. Member emergency communication involves:
  - using multiple dissemination channels
  - covering 10 planning, response, and recovery items (See Chapter 4. Case Management, Care Planning and Care Coordination)
  - analyzing gaps in existing emergency content
  - offering information in useable and understandable formats
  - helping members get, pay for, and use devices that enable internet connectivity
  - employing multiple methods to measure success

(See Chapter 5. Member Emergency Communication)

***Contractors and vendors agreements should:***

- integrate detailed accessibility and emergency planning, response, and recovery contract obligations for vendors and contractors
- contract with community-based organizations for assistance with member emergency services



(See Chapter 6. Contractor and Vendor Agreements)

***Participate actively in community partnerships to:***

- maximize effective response
- maintain active connections with community partners in planning, exercises, drills, response, and recovery activities
- organize the delivery of needed items
- coordinate life-safety checks by leveraging partnerships with organizations that maintain current lists of those who will be the most negatively and disproportionately impacted and need lifesaving, life-sustaining, and life-supporting assistance

(See Chapter 7. Community Partnerships)

***Workforce training should include:***

- increasing skills, giving permission to and showing employees how to problem-solve quickly during an emergency
- mentoring and providing feedback to employees
- refreshing content and materials frequently
- training teams
- elevating the importance of exercises
- spaced reinforced interval learning (not “one and done”)
- put greater or at least equal emphasis on just-in-time training
- use evaluation methods that measure performance, member impact, and outcomes

(See Chapter 8. Workforce Training)

## **Chapter Summary**

There are many ways state and federal regulators, and other advocates, influencers, and drivers of change can accelerate and increase the adoption of member-focused emergency health plan practices. However, it takes sustained political will and attention.



## Chapter 10. Roadmap Summary

The increasing scale and scope of emergencies appear to be here to stay as the new normal. The time is now to make changes to help members successfully cope with and live through these inevitable events.

Lasting change occurs and is measured over years. Creating and embedding emergency competencies, capabilities, and capacities into diverse health plan systems, contracts, staff and policy, is an iterative process. Effecting lasting change is incremental fueled by perseverance. This change involves multiple exposure activities, reinforcing sustained commitments to cultivating new and supporting old champions, training, technical support, continual quality improvements and policy change.

It is better to do something than nothing and to start somewhere. So, start small, grab the low-hanging fruit, hit the softballs, make small dents, and chip away at objectives. Use this Roadmap to evaluate current strengths and weaknesses, opportunities, and setting priorities.

The increasing scale and scope of emergencies appear to be here to stay as the new normal. The time is now to make changes to help members successfully cope with and live through these inevitable events.

### High Priorities

High priority implementation steps include:

- health plan leadership's commitment to pursue, strengthen, embed, and sustain member-focused emergency practices
- state and federal regulatory and statutory requirements that include effective oversight and enforcement to accelerate the adoption of member-focused emergency practices
- commitment to support research that documents the most promising, evidence-based interventions

### Future project activities

This project's next steps include securing funding to:



- update, illustrate, and professionally format this Roadmap
- develop a short, easily customized companion health plan checklist, which incorporates actionable steps from this longer comprehensive report
- pursue policy change opportunities to accelerate adopting member-focused emergency practices covered in this Roadmap
- facilitate a learning collaborative that brings together a small group of health plan members to promote small group problem solving and explore challenges, promising practices, promoting improvement in approaches and methods.





## Appendix A: Acknowledgments

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17. Carolina Coleman, LA Care
18. Jane Comody, John A. Hartford Foundation
19. Chris Duff, Disability Practice Institute
20. Stephanie Duke, Disability Rights Texas
21. Shona Eakin, Transitional Plans for Independent Living
22. Jennifer Echeverria Miyamoto, Blue Shield of California Promise Health Plan
23. Alexandra Enders, Emergency Services Consultant
24. Tim Engelhardt, Centers for Medicare & Medicaid Services
25. Dulce Fernandez, LA Care
26. Dorothy Fleisher, W. M. Keck Foundation
27. Rick Fredrickson, Centene Corporation
28. Merrill Friedman, Amerigroup



29. Dee Grimm, Tenebo Enterprises
30. Susan Havercamp, The Ohio State University Nisonger Center
31. Dennis Heaphy, Health Policy Analyst
32. Bill Henings, Boston Center for Independent Living
33. Sandy Ho, Brandeis University
34. Martha Hodgesmith, Health Plan and Community Based Services Consultant
35. Todd Holloway, Center for Independence
36. Lisa Hayes, Rolling Start, Inc.
37. Ami Hyten, Topeka Independent Living Resource Center
38. Mark Johnson, Shepherd Center
39. Megan Juring, Aging and Disability Policy Consultant
40. Marti Kaplan, Organization Development Consultant
41. Carmen Katsarov, Blue Shield of California Promise Health Plan
42. Lou Ann Kibbee, SKIL Resource Center
43. Allan Kyle, Centers for Medicare & Medicaid Services & Administration for Community Living
44. Rosa Leiva, Blue Shield of California Promise Health Plan
45. Lisa Lezzoni, Health Policy Research Center, Mongan Institute, Massachusetts General Hospital
46. Mary Lockeyer, American Red Cross
47. Karen Luken, Disability and Health Consultant
48. Chris MacDonell, Medical Rehabilitation and International Aging Services/Medical Rehabilitation
49. Erika McConduit, Centene Corporation
50. Christina Mills, California Foundation for Independent Living Centers
51. Jean Minkel, Independence Care System
52. Jennifer Echeverria Miyamoto, Blue Shield of California Promise Health Plan
53. Kristin Murphy, Centene Corporation
54. Mary Beth Musumeci, Kaiser Family Foundation
55. Kay Noyes, CalOptima
56. German Parodi, The Partnership for Inclusive Disaster Strategies
57. Richard Petty, IL-NET National Training and Technical Assistance Center for Independent Living at ILRU
58. Carmen Ramirez, Inland Empire Health Plan
59. Stephanie Rassmussen, Sunflower Health Plan
60. Krista Riganti, Blue Shield of California Promise Health Plan
61. Abby Ross, United Spinal Association



62. Marcie Roth, World Institute on Disability
63. Maggie Shreve, Organization Development Consultant (formerly at Rush University Medical Center)
64. Aimee Siebert, Colorado Department of Public Health
65. Dawn Skaggs, World Institute on Disability
66. Shaylin Sluzalis, The Partnership for Inclusive Disaster Strategies
67. Joycelyn Smart-Sanchez, Blue Shield of California Promise Health Plan
68. Ann Thompson, Kaiser Permanente of Southern California
69. Serena Thompson, Anthem
70. Meg Traci, The University of Montana Rural Institute
71. Sarah Triano, Centene Corporation
72. John Tschida, The Association of University Centers on Disabilities
73. Gary Ulicny, GRU Healthcare
74. Ted Webster, Centene Corporation
75. Erin Westphal, The Senior Care Action Network SCAN Foundation
76. Bobbi Wunch, Pacific Health Consulting Group

## Appendix B: Feedback

The author invites your feedback to inform and contribute to future Roadmap editions. Copy and paste these questions into an e-mail with your answers. This questionnaire is also available for copying at [www.jik.com/roadmap-feedback.html](http://www.jik.com/roadmap-feedback.html)

**To:** June Isaacson Kailes, [jik@jik.com](mailto:jik@jik.com)

**Subject:** Roadmap feedback

I practice in and represent these disciplines and organizations (check all that apply):

- Health plans
- People with disabilities
- Contractors and consultants
- Disability-led organizations
- Researchers
- Emergency management agencies
- Government agencies
- Foundations or Trusts
- Accrediting / standard-setting organizations
- Other: specify \_\_\_\_\_

How did you or will you use this "Roadmap?"

What insights did you gain?

What sparked new, revised, or enhanced practices where you work?

Suggestions for improving (e.g., what additional information would you like to see?)

Other comments:

**Optional:** If we may quote you, please provide your name, title, and organization:

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## Appendix C: Interview Questions

These questions relate to the member-focused roles of health plans before, during, and after emergencies. They are not about the continuity of operations plans (COOPs) that center on operations through emergencies (access to data, facilities, mutual aid, etc.).

I do not expect you to answer all these questions. I want to get your ideas regarding the areas you know or in which you have experience. I may probe further with each question, depending on how our dialogue is going.

1. What are your projections or thoughts about **how** innovative and promising practices could be integrated into ongoing procedures for COVID-19 and other emergencies into member-focused emergency planning, response, and recovery?

Some examples:

- **Care coordination** and case management
- **Work with members** to develop and maintain personal emergency plans that incorporate
  - low cost and no-cost actions such as planning with personal support or help teams (family, friends, personal attendants, caregivers)
  - plan for alternative methods of powering life-sustaining equipment, communicating, evacuating
- **Prioritizing and conducting life-safety checks** to address complex independent living and health needs of individuals who lack support from family, friends, and others, are geographically isolated, are least able to receive, understand or act on emergency alerts, are power-dependent on life-sustaining equipment (respirators, ventilators, mobility devices), require oxygen, dialysis, chemotherapy, or other essential infusion therapies, are least able to get to pharmacies and distribution sites for power, food, water; diverting unnecessary admissions to hospitals and nursing homes; replacing devices, equipment, supplies, and medications.



- **Delivery of water, food, and other supplies** for those unable to get to or use points of distribution
  - **Telehealth delivery and when needed providing devices,** technical support, and assistance with paying for connectivity
2. Are you aware of specific health plan interventions that keep people out of nursing homes during emergencies?
  3. Are you aware of promising practices regarding Community Partnerships with local emergency partners inclusive of government, businesses, vendors and providers, and community service organizations?
  4. Do you know of any existing member-centered emergency guidance for the industry?
  5. Do you know of or do you anticipate new state health plan contract member-focused emergency requirements?
  6. Would you be willing to review and provide feedback on a draft of the final guidance document?
  7. What organizations are missing from this list regarding disseminating this project's products and findings via conferences, email, list serves, and social media? Which three would you judge to have the most impact from a presentation?
    - American Association of Public Health (APHA)
    - America's Health Insurance Plans (AHIP)
    - Applied Self Direction (ASD)
    - California Collaborative for Long Term Services and Supports (CCLTSS)
    - CMS Centers for Medicare and Medicaid Services
    - Corada, the Comprehensive Online Resource for the ADA
    - Leaders Engaged on Alzheimer's Disease (LEAD Coalition)
    - Long Term Quality Alliance
    - National Association of Area Agencies on Aging (n4a)
    - Medicaid Managed Care Congress
    - Medicaid Health Plans of America (MHPA)
    - National Alliance for Caregiving
    - National MLTSS Health Plan Association National Quality Forum



- National Resource Center for Participant-Directed Services (NRCPPDS)
- Partnership for Medicaid Home-Based Care
- The Commonwealth Fund's Health Care Delivery System Reform Program
- The National Association of States United for Aging and Disabilities
- MLTSS Institute
- Resources for Integrated Care
- U.S. Department of Health & Human Services Office of the Assistant Secretary for Preparedness & Response (ASPR)

8. What questions should I have asked?

9. Who else should I consider interviewing?

10. Do I have your permission to acknowledge you in the final product as one who was interviewed (nothing will be attributed to you without your permission)? If yes, is this accurate:



## Appendix D: References

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<https://www.improvingpopulationhealth.org/blog/what-is-population-health.html>

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[Medical Surge and the Role of Health Clinics](#), The U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response (ASPR) Technical Resources, Assistance Center, and Information Exchange (TRACIE) 2018, pp.15, 29 (accessed 8.1.21)

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Robbins, Salomon & Patt, Ltd. [Seeks justice for Michael Hickson, Files wrongful death lawsuit against St. David's South Austin Medical Center and](#)



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[One Man's COVID-19 Death Raises the Worst Fears of Many People with Disabilities](#)

July 31, 2020, 3:29 PM ET, heard on NPR's [Morning Edition](#)

As Hospitals Fear Being Overwhelmed By COVID-19, Do the Disabled Get the Same Access? NPR's All Things Considered, 12.14.03. (accessed 11.06.21)

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[Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters](#) (accessed 6.19.21)

Aunt Bertha, A Public Benefit Corporation, is a social service search and referral service in Austin, Texas. The company serves customers across the United States, ranging from healthcare systems, payors, higher education, housing developments, and more. Links to "Aunt Bertha" vary by state.

[Unite Us - Building Healthier Communities](#) - Creating an efficient system of care within the community to improve health. The only end-to-end solution for social care. Social Determinants. Patient Centered Care. Coordination Software. Software Solutions. (accessed 10.17.21)

Emergency Preparedness Requirements for Medicare and Medicaid participating providers and suppliers. ([CMS Emergency Preparedness Rules](#)) (accessed 6.27.21)

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[Power Outage Fact Sheet](#) (accessed 8.3.21)

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## Appendix E: Resources

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[Health-Care Organizations Expand Their Emergency Management](#), Government Technology (online). Focus more on healthcare institutions that are investing resources to design, launch, and sustain an integrated continuity of operations program. Scott W. Ream, November 21, 2011 (accessed 7.7.21)

[Home and Community-Based Services](#), 2020 U.S. Centers for Medicare & Medicaid Services (accessed 7.11.21)

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[Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters](#), 2019, National Council on Disability (accessed 7.11.21)

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[Medical Surge and the Role of Health Clinics](#), The U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response (ASPR) Technical Resources, Assistance Center, and Information Exchange (TRACIE) 2018, p.29 (accessed 8.1.21)

Waivers and Flexibilities [Emergency Preparedness and Response for Home and Community Based \(HCBS\) 1915\(c\) Waivers](#) (accessed 6.30.21)

[Home and Community-Based Services \(HCBS\)](#) are types of person-centered care delivered in the home and community. HCBS programs address the needs of people with functional limitations who need assistance with everyday activities, like getting dressed or bathing. HCBS enables people to stay in their homes rather than move into a facility for care. HCBS are less than half the cost of traditional institutional care. (accessed 6.30.21)

[Identifying “Rising Risk” Populations: Early Lessons from the Complex Care Innovation Lab](#) - CHCS Blog, Center for Health Care Strategies, August 20, 2020 (accessed 8.28.21)

Inland Empire Health Plan - Using Location Intelligence to Monitor IEHP Members, Providers, and Facilities During Wildfires or Power Outages in [Sixth Annual Innovation Award for Medi-Cal Managed Care Health Plans](#), October 2020 (accessed 6.30.21)

[Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical](#) 2019 (accessed 7.20.21)

[Durable Medical Equipment in Disasters](#) ASPR TRACIE. (2018) provides general durable medical equipment (DME) categories and focuses on electricity dependent DME that may be power affected by disasters and emergencies, including power failures, includes information to assist healthcare system plan with people who rely on DME (accessed 5.3.21)

[Emergency Health Information: Savvy Health Care Consumer Series](#) (2011) how to develop emergency health information, keeping copies of this information in a wallet (behind driver’s license or official identification card) and emergency kits. It shares with rescuers important information when an individual is unable to provide information, contains information about medications, equipment, allergies, communication needs, preferred treatment, medical providers, and emergency contacts. (accessed 7.10.21)



[Emergency Supplies Kits for People with Disabilities and Activity Limitations](#), Edition 2.0, (2016) Checklist suggests emergency kit contents including no-cost supplies that you can tailor to your needs and abilities. Kits to consider for different places and situations: keep it with you, grab and go, home, bedside, and car. Specific suggestions for hearing, speech and communication, and vision issues and wheelchair and scooter users, service animal owners, and people with allergies, chemical sensitivities, and breathing conditions. (accessed 7.10.21)

[Pathways to Community Living](#), June 2021 (accessed 8.29.21)

[Roads to Freedom Transitions](#), Center for Independent Living – Washington State, June 2021 (accessed 10.9.21)

[COVID-19 in Institutions: \(STILL\) Dying in Place; Saving Lives During Emergencies](#) 7/14/21, This virtual event brings together Federal and State Agencies, Centers for Independent Living and people with disabilities to discuss all the aspects of saving lives during emergencies. People with disabilities continue to suffer deep losses and disproportionate death during the COVID-19 Pandemic. Presenters discuss what went wrong; what was done right and most importantly, how to ensure lives are prioritized and saved. (accessed 7.15.21)

[Know Your Rights Guide to Surviving COVID-19 Triage Protocols](#) (accessed 7.1.21)

[Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability](#) (accessed 7.1.21)

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[“Don’t Deny Disabled People Ventilators” op-ed by National Council on Disability Chairman Neil Romano and Sam Bagenstos](#) 4/6/20 (accessed 7.1.21)

[Be Real, Specific, and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs](#), Edition 1.0, (2016)

[Health Care Rights for People with Disabilities \(2015\)](#) (accessed 7.10.21)  
Health plans must provide access to health care services, including



preventive care and necessary services. California's Department of Managed Health Care provides this content to help Californians with disabilities understand their rights and get the care they need. Topics include:

[Physical Access to Care](#)

[Communication Assistance - Hearing](#)

[Communication Assistance - Hearing-Deaf](#)

[Communication Assistance - Vision](#)

[Getting Health Care Benefits and Services](#)

[Rewordify.com](#) - a free, online tool that simplifies difficult English for better understanding (accessed 8.7.21)

[plainlanguage.gov](#) - guidelines that help with writing clearly so readers can:

- find what they need
- understand what they find
- use what they find to meet their needs (accessed 8.7.21)

[Centers for Disease Control and Prevention \(2014\)](#) Evidence-based tools can help healthcare emergency communications staff create and assess communication products on topics for diverse audiences. Users provide information about seven key communications areas (e.g., main message, behavioral recommendations), and the Index provides an overall score. (accessed 5.3.21)

Centers for Disease Control and Prevention. (2016). [Everyday Words for Public Health Communication](#) (accessed 5.3.21)

[National Resource Center on Advancing Emergency Preparedness for Culturally Diverse Communities](#), Drexel University. (2008) focuses on disaster preparedness in culturally diverse communities. Materials include six categories: Community, Type of Emergency, Resource Type, Language, U.S. Region, and those that fall under Multiple Categories (accessed 1.3.19)

Public Health - Seattle & King County and Northwest Center for Public Health. [Texting for Public Health: Emergency Communication, Health Promotion, and Beyond](#). The toolkit helps plan for and implement text messaging programs for emergencies and more general health promotion.



Covers: why text messaging is effective, getting people to subscribe, legal issues, and technological options. (accessed 1.3.19)

[Language Is More than a Trivial Concern!](#) (2010) gives appropriate terminology to use when speaking with, writing about, or referring to people with disabilities. Challenges readers to be aware of the importance of using disability-neutral terms. Details preferred language and gives reasons for the disability community's preferences. Serves as a reference tool for the public, media, marketers, providers, board members, staff, and volunteers of disability-related organizations. Includes a language quiz and many examples. (accessed 7.10.21)

[Competency Planning Checklists for Providing Health Care for People with Disabilities](#) (2016) See section on Communication Access pages 8-14, and Communication access resources pages 19-22. (accessed 7.10.21)

[Improving the Accessibility of Social Media in Government](#) covers agencies' responsibilities to ensure that digital services are accessible to all people with disabilities. Includes recommendations for improving accessibility of social media, tips for making Facebook posts accessible, Tweets accessible, YouTube videos accessible; and resources, training, and how to provide feedback (2013) (accessed 7.10.21)

[Section 508 of the Rehabilitation Act](#) requires access to electronic and information technology procured by Federal agencies (accessed 7.10.21)

The [ICT Testing Baseline for Web Accessibility](#) sets minimum testing criteria and evaluation guidelines to determine if web content meets the 508 Standards that incorporate by reference the Web Content Accessibility Guidelines (WCAG) 2.0 Level A.A. Issued by the W3C's Web Accessibility Initiative, WCAG 2.0 is a globally recognized, technology-neutral standard for web content (accessed 8.4.21)

[Web Accessibility Initiative \(WAI\)](#) Web provides strategies, guidelines, resources to make the Web accessible to people with disabilities (accessed 7.10.21)

[Social Media](#): The use and impact of social media platforms (e.g., Twitter, Facebook, LinkedIn, Snapchat, and YouTube) has skyrocketed over the past decade and has significantly supplemented—if not nearly replaced—more traditional means of communication in many areas of the U.S. Recent





disasters have highlighted the level to which people use social media to give and get information. (accessed 6.19.21)

Arthur J. Gallagher & Co. (2014).). [Social Media and Disaster Communications Checklist.](#)

This checklist helps emergency planners create a social media plan. It includes steps before, during, and after a disaster and links to social media platform pages. (accessed 7.28.21)

[Be Ready to Go: Evacuation Transportation Planning Tips for People with Access and Functional Needs](#) (2010) (accessed 7.14.21)

[Be Ready to Go: Disability-Specific Supplies for Emergency Kits \(2010\)](#) (accessed 7.14.21)

[Emergency Evacuation Preparedness: Taking Responsibility for Your Safety, A Guide for People with Disabilities and Other Activity Limitations \(2002\)](#) (accessed 7.14.21)

- create, review and practice plans
- gather emergency health information
- evaluate need to identify people who will need help during an evacuation
- practice the skill of giving quick information on how to best assist you
- establish personal support networks
- conduct an ability self-assessment
- know your emergency evacuation options

[Emergency Health Information: Savvy Health Care Consumer Series \(2011\)](#) guides you through developing emergency health information. You should keep copies of this information in your wallet (behind your driver's license or official identification card) and emergency kits. It shares with rescuers important information about you if you are unable to provide information. It contains information about your medications, equipment, allergies, communication needs, preferred treatment, medical providers, and emergency contacts. (accessed 7.10.21)



[Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical \(2019\)](#) (accessed 7.10.21)  
Emergency power planning checklist is for people who use electricity and battery-dependent technology and medical devices, such as:

- breathing machines (respirators, ventilators),
- power wheelchairs and scooters, and
- oxygen, suction, or home dialysis equipment.

Some of this equipment is critical to maintaining independence, while other equipment is vital to keeping members alive! Use this checklist to make power-backup plans, including:

- how to establish a support team
- how to master the skill of giving quick information on how best to help you
- advice from users and
- sources for more information

[Emergency Preparedness for Personal Assistant Services \(PAS\) Users, Edition 2.0, \(2016\)](#) includes:

- tips specific to individuals who use personal assistants, attendants, or caregivers
- a checklist
- “how to” details about support teams, communication, evacuating and sheltering, and supplies. (accessed 7.10.21)

[Emergency Preparedness: Taking Responsibility for Your Safety - Tips for People with Activity Limitations and Disabilities \(2006\)](#) (accessed 7.10.21)

[Emergency Supplies Kits for People with Disabilities and Activity Limitations, 2010, Edition 2.0, \(2016\)](#) (accessed 7.10.21) Checklist suggests emergency kit contents, including no-cost supplies that you can tailor to your needs and abilities. Kits to consider for different places and situations: keep it with you, grab and go, home, bedside, and car. Specific suggestions for hearing, speech and communication, vision issues, wheelchair and scooter users, service animal owners, and people with allergies, chemical sensitivities, and breathing conditions.



[Out-of-town emergency contacts listed in priority order \(the first person reached calls all others on this list\) \(2015\)](#) (accessed 7.10.21) [Assist in preserving the health and safety of individuals with spinal cord injury](#) in times of uncertainty and upheaval due to natural or human-caused disasters through advanced planning, along with the preparation of professionals and local agencies. Being intellectually and physically equipped for unexpected events can save lives, lessen the emotional impact, and facilitate a quicker adjustment in times of transition (accessed 7.10.21)

The Inland Empire Health Plan member website is an example of how this information can be used. <https://iehp.org/en/members/helpful-information-and-resources> (accessed 8.22.21)

[Healthcare Ready](#) is an interactive map that shows open and closed pharmacies in areas affected by emergencies.

See Mobile Devices for Telehealth/Virtual Care in [Sixth Annual Innovation Award for Medi-Cal Managed Care Health Plans, October 2020, California Department of Health Care Services](#) (accessed 6.19.21)

[Tips for Emergency Use of Mobile Devices Edition 2, \(2015\)](#) - Cell phones, smartphones, and other mobile wireless devices like tablets are a big part of our lives. We rarely leave home without them, and we often store vital information on them. In a small or large emergency, they can be a communication lifeline. Provides details regarding preparing your device to quickly get and give emergency information, including a checklist, emergency contacts and documents, alerts, texting, apps, bookmarks of important mobile sites, "no service" backup plans, skill drills, and other resources (accessed 6.19.21)

[Effectively Including People with Disabilities in Policy and Advisory Groups \(Edition 2, 2012\)](#) (accessed 7.14.21)

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. This system makes assistive technology devices and services more available and accessible to individuals with disabilities and their families. Each state, the District of Columbia, Puerto Rico, and the territories (American Samoa, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands each gets one grant (accessed 6.12.21)



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- [flowchart and assessment tool](#) for making decisions about using a registry
- Defines [what registries are](#), and the types of registries used in emergency management
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