THE PARTNERSHIP
FOR INCLUSIVE DISASTER STRATEGIES

Getting It Wrong: An Indictment with a Blueprint for Getting It Right

Disability Rights, Obligations and Responsibilities Before, During and After Disasters

Edition 1; May 2018

Figure 1: A collage of four images: A) A woman using a wheelchair is assisted through heavy flooding; B) Two people smile for the camera during disaster recovery efforts; C) A man using a wheelchair maneuvers through heavy flooding; D) Supplies are dropped from a helicopter.

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EXCERPT - HEALTH PLAN RECOMMENDATIONS

3.4 Health Plans

Many of the key informants for this section represent Medicaid Managed Care Health Plans. Most of the content pertains to all health insurance carriers as well as organizations that focus on supporting the health and health care of people with disabilities and others with access and functional needs. This includes non-governmental organizations and government agencies such as the Veterans Administration, local disability service providers, disability-specific organizations (muscular dystrophy, cerebral palsy, multiple sclerosis, blind, deaf, hard of hearing, autism, mental health, developmental disability, etc.), Easter Seals, community clinics, Federally Qualified Health Centers, equipment vendors, and home health agencies.

Health plans in this report refer to health insurance plans across all lines of business: employer-sponsored coverage, individual insurance market, and public programs (Medicare and Medicaid). Health plans can serve a critical role in life-saving and life-sustaining interventions and mitigating these disruptions and disproportional impacts.

Health plans such as Anthem Blue Cross Blue Shield, Amerigroup, Superior Health Plan in Texas and Sunshine Health® in Florida (Superior and Sunshine are wholly-owned subsidiaries of Centene Corporation) are examples of plans that quickly activated their emergency response plans. This operationalizing included, but was not limited to: messaging, life-safety checks, member tracking, quickly sharing critical

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health information, preventing and diverting inappropriate admissions to medical facilities and institutionalization, and commitment to the continuous strengthening of their emergency plans during and after their response.

Examples of some of these health plans' promising practices are described throughout this section as well as reflected in the recommendations that follow. A common thread emerged. These health plans, and probably others we lacked time to identify, had a strong "perception of threat." These plans operate from the "not if, but when" risk of real and reoccurring disasters. These health plans acknowledged that their members live in high hazard threat and disaster probability areas. Because of this, these health plans have robust policies, training, processes, procedures and protocols.

All health plans should be proactive in addressing the inevitable degrading or failure of critical member personal support systems during disasters, which include equipment, supplies, technologies and customized environments that typically work in non-emergency times. These support interventions have direct and substantial impact on the health of their members, and their degradation and failure has a devastating impact on the health, safety and independence of their members.

Rapid health plan response can also mitigate the disturbing trend in disasters of transfer of people with disabilities who lived in the community to institutional settings because of planning failures including lack of health care options, post-shelter housing options and difficulties these individuals have in accessing and navigating the complex maze of disaster recovery assistance.

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The speed at which health plans activate their emergency response plans has a direct correlation to life-sustaining outcomes for many who can be disproportionately impacted. Rapid health plan response can also mitigate the disturbing trend in disasters of transfer of people with disabilities who lived in the community to institutional settings because of planning failures including lack of health care options, post-shelter housing options and difficulties these individuals have in accessing and navigating the complex maze of disaster recovery assistance.

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Recommendation Part IV – Section 3.15

Emergency Preparedness Should Include Member Needs.

Health Plan Roles

Health plans emergency preparedness must go beyond the implementation of business continuity plans to also include member needs.

Planning

Call Centers

Establishing call center emergency protocols including just-in-time training, developing and use of scripts, and processes for escalating callers through warm internal hand-off connections for members needing immediate critical assistance, especially when local first response and government's 911, 211, and 311 call centers are not functioning (power, connectivity, staffing) or not functioning well (overwhelmed and long wait times).

Community Partnerships

Establish and maintain active connections with community partners in planning, exercises, drills, response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

Anthem quickly contracted with Portlight and the Partnership for Inclusive Disaster Strategies to increase the effectiveness of member outreach services. This partnership was built on trust resulting from an existing relationship of several years. This agreement collaboration pairing Anthem's health care expertise with Portlight's: disaster response competencies, deep understanding of the complexities and nuances of the lived disability experience, and strong and current connectedness to other local and self-organized responders (such as the Cajun Navy) helped us respond more quickly and support people in their communities. "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," explained Merrill A. Friedman, Senior Director, Disability Policy Engagement, Federal Affairs, Anthem, Inc.

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Member Emergency Plans

Health plan care coordinators and case managers should be required to assist members to develop and sustain personal emergency plans. All three health plans interviewed for this After Action Report incorporated personal emergency plans into their members' care plans. This included planning for power outages, an extra supply of medication, evacuation, sheltering-in-place, and identification of support systems. For example, Florida's contract with Medicaid health plans requires that a well-documented emergency plan is in place for members. Sunshine Health® reviews these plans with members every 90 days.

Posting and Disseminating Emergency Preparedness Information

Posting and disseminating emergency preparedness information for members, family members, personal assistance and caregivers is also important. 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 sufficient for people with disabilities. Materials can be more inclusive when they contain information that focuses on specific functional needs, in addition to health (hearing, vision, mobility, speech) and cognition (thinking, understanding, learning, remembering) and also on no-cost and low-cost preparedness strategies in addition to costly activities. These no-cost preparedness activities include: identifying support teams and evacuation plans, collecting emergency health information and emergency documents and discussing these plans with personal attendants/ family and significant others, and exercising and updating plans to align with current health and functional needs.[22] [23] [24] [25]

A critical focus of such plans should include member power backup planning and improving the resilience of people living independently who depend on power and battery- dependent life-sustaining equipment and mobility equipment. Examples include breathing machines (respirators, ventilators, CPAP and nebulizers), power wheelchairs and scooters, and oxygen, suction, nutrition or home dialysis equipment.)[26] [27] Users need clear instructions regarding backup power options for batteries as well as supplying and charging extra batteries, where indicated.

Recommendation Part IV – Section 3.16

> **Health plans should require their contracted vendors and providers to thoroughly and often instruct users regarding emergency procedures for their equipment.** Their instructions and training protocols should be regularly assessed for accuracy and effectiveness.

Life-safety Checks

Superior Health Plan 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 when needed to complete such tasks as filling prescriptions early and have their grab and go bags and evacuation plans ready.

Sunshine Health® care coordinators helped members pre-hurricane to board up windows and post-hurricane they delivered food, water, oxygen, medications, equipment, and supplies via face-to- face visits. They shipped meals, tracked where the power grid was down and made in-person visits to those areas a priority. Because emergency information is often changing, Sunshine Health® created

[22] Kailes, J. I. (Edition 1.0, 2016) Be Real, Specific, and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs (PDF)
[23] Kailes, J.I. (Edition 2.0, 2016) Emergency Preparedness for Personal Assistant Services (PAS) Users (PDF)
[24] Kailes, J.I. (Edition 2.0, 2016) Emergency Supplies Kits for People with Disabilities and Activity Limitations (PDF)
[25] The American Journal of Managed Care > January 2015 – Published on: January 16, 2015 State of Emergency Preparedness for US Health Insurance Plans Raina M. Merchant, MD, MSHP; Kristen Finne, BA; Barbara Lardy, MPH; German Veselovskiy, MPP; Casey Korba, MS; Gregg S. Margolis, NREMT-P, PhD; and Nicole Lurie, MD, MSPH
[26] Kailes, J.I. (2013). Emergency power planning for people who use electricity and battery dependent assistive technology and medical devices. Pacific ADA Center.
[27] Kailes, J.I (2009). Emergency Safety Tips for People Who Use Electricity and Battery-Dependent Devices

an internal centralized point, called “Response Central”, for staff to get current and reliable updates to frequently changing information.

Members with pre-identified serious gaps in their emergency plans and those with complex health needs were prioritized by all three health plans into a tiered system which enabled first contacting members projected to be the most disproportionately impacted.

This first contact group included members with complex health care needs, who may not be able to get or understand emergency alerts, need dialysis, chemo and temperature regulated medication (insulin and biologics, for example), who are dependent on power to operate essential life-sustaining equipment and motorized mobility devices, who lack emergency support from family, friends or others, who are in need of food, water, oxygen, medications, power, equipment, and supplies and who are unable, or least able, to get to commodity distribution points.

These three health plans dispatched service coordinators to conduct in-person life safety checks when members could not be reached. Anthem distributed cell phone solar chargers and bottled water, when needed, to members during these visits. These health plans also instituted member tracking when evacuations resulted in transport to another county or state.

Health Information Exchange

Planning for methods to quickly share health information that is critical to a member’s life and essential continuity of care. Training staff regarding when and how to apply the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule in emergencies.

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Transitions

Preventing and diverting inappropriate admissions to medical facilities and institutionalization.

Assisting members who get caught in the institutional net to move back **into the homes and communities of their choice**.

- Problem-solving and marshalling resources to meet urgent needs and anticipate surmounting geographical and logistical challenges to provide notification, actionable instructions, evacuation, rescue, accessible transportation, sheltering and health care.

- Organizing matches of critical needs with delivery of needed items damaged, destroyed, lost, or left behind: delivery of food, water, generators, fuel, equipment, supplies, medication, mobility devices (wheelchairs, canes, crutches, walkers, shower chairs, raised toilet seats) and technology.

- Helping with transitions back home, or to temporary and new homes through exercising flexibility in funding of nontraditional services like emergency evacuation, disaster case management to navigate disaster programs, air conditioners and air filters, mold removal, reconstruction of ramps, accessible showers, debris removal, loaned and expedited replacement of disability equipment, transportation for food and repair shopping, etc.

Messaging

Communicating with members using multiple dissemination channels: email, text, website and social media, public service announcements, outbound calls.

Creating prewritten messages (pre-tested for clarity) ready to be customized and finalized per the event.

Messages include details regarding:

Pre-emergency

Proactive reminders to members to review and have ready emergency plans for sheltering-in-place and evacuation and how to refill prescriptions early

During and post emergency

- How to reach the health plan, care coordinators, nurse hotline, telehealth services.
- How and where to go when primary pharmacy, dialysis centers or chemo and other infusion therapy sites are not available.
- Relaxing benefit restrictions such as: priority medical authorizations, out-of-network care, medication refills, durable medical equipment loans and replacement, getting an emergency supply of medications, and medical record access.
- Where to get behavioral health or mental health services, i.e., counseling.
- Guidance for addressing disruptions to in-home support for children and adults with autism, mental health and similar support needs to prevent acute hospitalization or institutional placement.
- Reliable, tailored situation updates compiled from public and private sources
- Portals for members during emergencies can be very helpful:
- Medications:
    - Healthcare Ready activated it's free, interactive RxOpen map to show open and closed pharmacies in the region affected by Hurricane Harvey. Citizens and first responders were encouraged to use this map as an initial resource, and to call their pharmacy to ensure their specific medication was in stock.
    - Payer hotlines and assistance information (PDF)
- Pharmacy Resources
    - Many laws for prescription refills are modified during emergencies such as during Hurricane Harvey. Contact numbers for insurance companies that may be able to help with prescription coverage were provided even if the individual did not have

their insurance card.

- Kidney Dialysis
    - Kidney Community Emergency Response (KCER) Coalition
    - KCER Hotline: 866.901.3773
- Health Plans (sample)
    - Anthem Blue Cross Blue Shield: Help for Members Impacted by Hurricane Harvey in Texas and Louisiana
- Superior Health Plan –Texas: SUPPORT FOR SUPERIOR MEMBERS AFFECTED BY RECENT STORMS

Anthem provided members and non-members with a free 24-hour nurse hotline and online access to a doctor for assistance with a specific medical, mental health and behavioral health issues at www.livehealthonline.com. Kiosks at various locations also offered this service via Telehealth (video connection with doctors) and included blood pressure measurement. The Anthem wheelchair accessible mobile health clinic in Houston, donated by American Well, had one of these kiosks.

Sunshine Health® is working to strengthen partnership with Centers for Independent Living. They are piloting this approach with the Miami Center for Independent Living serving the same Medicaid population to optimize shared 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.

Quality Improvements

Having in place a system to evaluate response outcomes, successes, as well as mechanisms that incorporate new learning into future emergency response protocols.

Recommendation Part IV – Section 3.17

States Should Incorporate Emergency Roles and Responsibilities into Health Plans Contracts.

Detailing the emergency roles and responsibilities of health plans, detailed above, into state contracts will have to foster a stronger health plan emergency response.

Recommendation Part IV – Section 3.18

Industry-Wide Guidance, Training and Technical Support

The rapid stand up of member emergency services could use industry-wide guidance, training, technical support, and regulatory standards such as the CMS Emergency Preparedness Rule.

Recommendation Part IV – Section 3.19

Integrate Specific Emergency Performance Clauses into Vendor and Contractor Agreements.

Health plans should integrate specific emergency performance clauses into their vendor and contractor agreements which includes compliance with the CMS Emergency Preparedness Rule. Health plans should also audit vendors and contractors for compliance. These audits should be conducted by individuals who are qualified to thoroughly review emergency plans for realistic, actionable and tested elements.

Recommendation Part IV – Section 3.20

Connect with Community Partnerships for Planning, Exercises, Drills, Response, and Recovery Activities. Health plans should actively connect with and support disability inclusive community partnerships, with emphasis on including disability-led groups, throughout planning, exercises, drills and response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

Recommendation Part IV – Section 3.21

Establish and Test Agreements for Emergency Supply Delivery and Evacuation Services.

Establish and test agreements with emergency supply delivery and evacuation services, for example, utilizing existing military and non-government public safety capability to deliver medications, life-sustaining supplies and equipment. These agreements can prevent a slow or failed response which has been shown to result in a preventable cascading exacerbation of what are typically well controlled chronic health conditions. This failure led to many unreported and under-reported deaths.

Recommendation Part IV – Section 3.22

Need for Evidence Based Emergency Plan Research (See Long Term Care Facilities Emergency Plans)

Recommendation Part IV – Section 3.23

Internal Emergency Procedures are Inclusive of Staff and Visitors Who Have Access and Functional Needs

Health plans should ensure that their internal emergency procedures are inclusive of staff and visitors with access and functional needs. For example:

Health plans should have inclusive procedures in place regarding evacuation of staff and visitors who will need evacuation or other assistance (those who have a have a variety of disabilities - mobility, breathing, allergies, hearing, seeing, reading, understanding) or chronic conditions and may have difficulty or be unable to:

- use stairwells
- hear alarms
- see or read exit signs

- understand written or verbal instructions
- take personal protective measures
- move to safety

Agreements

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Recommendation Part IV – Section 3.24

Connect with Community Partnerships for Planning, Exercises, Drills, Response, and Recovery Activities.

Health plans should actively connect with and support disability inclusive community partnerships, with emphasis on including disability-led groups, throughout planning, exercises, drills and response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

Recommendation Part IV – Section 3.25

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Emergency Plans for Long Term Care Facilities

Long term care facilities are a diverse group of licensed care facilities, congregate care, residential facilities, nursing homes, assisted living, group homes, intermediate care, senior housing, etc. Many of these facilities have insufficient emergency plans, and many more have no emergency plans at all.

The federal government's Centers for Medicare & Medicaid Services (CMS) Emergency Preparedness Rule provides regulations and guidelines for many of these and other facilities, as do the states. Enforcement is up to the states. Failure to comply may affect the facility's Medicare or Medicaid reimbursement. For nursing homes, states are required to perform unannounced inspections of every facility. The state's review of each nursing home is subject to CMS approval.

Reference: What You Need to Know About Nursing Homes New regulations, growing competition and frailer residents mean the industry must evolve, by Kenneth Terrell, AARP Bulletin, November 2017.

“Some nursing homes had and deployed emergency plans that worked. …managers at Genesis HealthCare pulled out its emergency response plan. Following the playbook, they evacuated 67 residents at Oak Crest Center in Rockport before Harvey hit, and 103 residents from its Clairmont facility in Beaumont immediately after the storm.” Err on the side of caution,’’ says Genesis HealthCare CEO George Hager. “If there’s a chance for patients at risk, you evacuate to safer areas, even if it’s disruptive to patients who are sick and frail, and even if it may be difficult.” “Genesis executives from regions outside the storms served as drivers, shuttling residents from evacuated facilities to safe locations. Extra buses and U-Haul trucks were rented where needed. Genesis also provided evacuated Texas residents with backpacks filled with several days of their medications, copies of medical charts and a change of clothing. Dozens of staffers left their homes and families to accompany evacuated residents.”

New Medicare and Medicaid Guidelines

New Medicare and Medicaid guidelines were driven by the deaths of over 200 hospital and nursing home residents during Hurricane Katrina. New plans must include procedures to deal with everything from storms to cyberattacks. These regulations are inadequate unless paired with equally strong enforcement provisions that include actionable processes, procedures, protocols, policies and non-governmental organizations training and frequent live drills.

The CMS Emergency Preparedness Rule, which went into effect in November 2016, details **“Four Core Elements of Emergency Preparedness.”**

- Risk Assessment and Emergency Planning (Include but not limited to):
    - Hazards likely in geographic area
    - Care-related emergencies
    - Equipment and Power failures
    - Interruption in Communications, including cyber attacks
    - Loss of all/portion of facility
    - Loss of all/portion of supplies
    - Plan is to be reviewed and updated at least annually
- Communication Plan
    - Complies with Federal and State laws
    - System to Contact Staff, including patients’ physicians, other necessary persons
    - Well-coordinated within the facility, across health care providers, and with state and local public health departments and emergency management agencies.
    - Policies and Procedures
    - Complies with Federal and State laws
- Training and Testing
    - Complies with Federal and State laws
    - Maintain and at a minimum update annually

"A recent review of federal records found that nursing home inspectors issued 2,300 violations of emergency-planning regulations over the past four years nationwide. Nearly 1,400 nursing facilities were cited for neglecting upkeep on emergency power generators."[28]

Recommendation Part IV – Section 3.26

Develop Strong Qualifications for Emergency Plan Reviewers and Guidelines for Emergency Plans

To prevent minimalistic or cursory plan reviews, State departments responsible for long term care facilities licensing should develop essential and robust qualifications for emergency plan reviewers, and establish minimum guidelines for emergency plans that include clear performance measures and benchmarks for preparedness and corrective action plans.

Recommendation Part IV – Section 3.27

Conduct Meaningful Audits. State departments responsible for long term care facility licensing should conduct meaningful audits that examine to specifics of every facility's emergency plans related to, but not limited to:

- Compliance with the CMS Emergency Preparedness Rule
- Evaluating the ability to accept and appropriately serve additional admissions during emergencies;
- Developing and regularly updating memoranda of understanding with multiple "like" facilities of variable distances away (within 10 miles, 20 miles, neighboring city, and states) who have the space for (often using unconventional spaces like common areas and dining rooms) and agree to accept their residents in an emergency.
- Assessing realistically the numbers of staff who will remain and or return to work after a disaster;
- Assessing the adequacy of plans for supplementing staffing to meet the needs of residents and emergency admissions if needed; and
- Transportation provider agreements for evacuations.

Recommendation Part IV – Section 3.28

Provide Guidance, Training and Technical Assistance Regarding Long Term Care Facility Emergency Planning.

States and local governments responsible for long term care facility licensing should provide emergency planning guidance, training and technical assistance to ensure.

Recommendation Part IV – Section 3.29

[28] Are Nursing Homes Ready for the Next Natural Disaster? Recent storms have put the spotlight on emergency planning for patients, by Gary Strauss, AARP Bulletin, November 2017

Identify Discrepancies Between State and Federal Requirements

State departments responsible for licensing long term care facilities need to identify any discrepancies between state and federal requirements and work to reconcile them for consistent interpretations. For example, the federal and state requirements regarding the numbers and types of drills can be different.

Recommendation Part IV – Section 3.30

Need for Evidence Based Emergency Plan Research

Centers for Medicare & Medicaid Services

How can the Centers for Medicare & Medicaid Services (CMS) strengthen incentives and enforcement of emergency procedures?

Has CMS guidance been developed and disseminated regarding how to meet the needs of people displaced to other states in emergencies, including guidance for addressing Medicaid portability?

If yes, is it disseminated? If no, how will it be developed and when will it be disseminated?

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Emergency Plan Reviews

Most long term care providers have requirements for developing and maintaining emergency plans. Sometimes these plans lack the specificity, robustness and interconnectedness with local emergency systems that make for real versus symbolic plans (see section on symbolic planning under registries). A plan quickly reviewed by remote individuals working for licensing, certifying or accrediting organizations often lacks the capability to determine the fidelity of an emergency plan. Reviews by local emergency, public health and community services personnel who know their local resources can offer critical reality filters. Such a review can identify inadequate or inaccurate elements of the plans, sometimes based on false assumptions, that need attention. Without these filters, plans will continue to be subject to failure, with catastrophic results.

The imperative for a reliable process must be built into already over stretched workloads. Effective and comprehensive planning isn't optional. Penalties for failure are not enough to ensure the safety of the individuals served. Incentives for compliance need to be created and excellence needs to be rewarded.