



HURRICANE SANDY RECOVERY WORKSHOP SUMMARY REPORT:

Lessons Learned and Promising Practices for Home
and Community-Based Service Providers

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NACCHO
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Introduction

On October 29, 2012, Hurricane Sandy made landfall north of Brigantine, New Jersey. The storm caused water levels to rise along the eastern coast from Florida to Maine. The highest storm surges occurred in New Jersey, New York, and Connecticut, especially in the New York City metropolitan area. Eleven states in the Southern, Mid-Atlantic, and New England regions declared states of emergency. In total, Hurricane Sandy was directly responsible for 72 deaths. An additional 87 deaths were indirectly associated with the storm, with over half being “at-risk” populations affected by power outages.¹

The Department of Health and Human Services (HHS) is the principal federal agency with responsibility for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. HHS defines “at-risk” populations as individuals with access and functional needs that may interfere with their ability to access or receive medical care before, during, or after a disaster or emergency. Section 2814 of the Public Health Service Act defines at-risk individuals as “children, pregnant women, senior citizens, and other individuals who have special needs in the event of a public health emergency.” Other examples of at-risk individuals with access and functional needs may include, but are not limited to: individuals with disabilities; those with temporary or chronic medical conditions and dependencies on health care services and/or durable medical and assistive equipment; people with physical, sensory, behavioral and mental health, intellectual, developmental, and cognitive disabilities; and individuals with limited English proficiency, limited access to transportation, and/or limited access to financial resources to prepare for, respond to, and recover from an emergency.² Populations of individuals who fall within these definitions will have a number of additional needs to consider in planning, response, and recovery activities related to natural and man-made disasters.³

Increasingly, more Americans with access and functional needs live independently in the community and receive their supportive services in a home or community-based setting. The U.S. Supreme Court’s 1999 landmark *Olmstead* decision found the unjustified segregation of people with disabilities is a form of unlawful discrimination under the American’s with Disabilities Act (ADA). The Court ruled it unlawful to keep people with disabilities in segregated settings when they can live in a community setting. States are required to provide community-based services for people with disabilities who would otherwise be entitled to institutional services when: (a) such placement is appropriate; (b) the affected person does not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities. Home and Community Based Services (HCBS) providers are those agencies and organizations that “provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted

populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.”⁴ For people with disabilities or others with access and functional needs, the provision of HCBS offers the opportunity to receive services in a preferred setting- their own home or community rather than institutions or other isolated settings. Furthermore, the delivery of HCBS is important, representing 53% of all Medicaid long-term care spending in 2014. Protections afforded by the ADA and Olmstead decision also extend to emergency situations. Therefore, effective preparedness planning requires continuity of HCBS to ensure the health and well-being of individuals with access and functional needs.⁵ Because of this, it is important to ensure that HCBS providers are part of a community’s emergency planning process.

Following Hurricane Sandy, a U.S. District Court found that New York City did not sufficiently protect people with access and functional needs in the case of Brooklyn Center for Independence of the Disabled versus the City of New York. The parties reached a settlement, and the stipulations of that settlement called for improvements in the following areas: emergency sheltering, post-emergency canvassing, transportation, communications, power outages, disability/access and functional needs coordination, and high-rise evacuation. The stipulations also called for the establishment of a Disability Advisory Community Panel, intended as a “collaborative entity through which the City can gather expertise, input, and feedback from disability community organizations and members of the disability community regarding accessibility issues arising from current or future proposals related to enhancing emergency planning as it impacts people with disabilities.”⁶ The events that lead to this case demonstrated a need to engage HCBS partners in emergency planning activities and address any gaps in training, planning, or expertise.

To better understand some of these gaps, the National Association of County and City Health Officials (NACCHO), through an existing cooperative agreement with the Office of the Assistant Secretary for Preparedness and Response (ASPR), convened a workshop with HCBS and local health departments (LHDs) impacted by Hurricane Sandy. The purpose of this workshop was to highlight the HCBS organizations’ response to Hurricane Sandy and to identify challenges, innovations, and promising practices for promoting community resilience and recovery. This workshop focused on HCBS providers from the New York, New Jersey, and Connecticut tri-state area due to the significant impact Hurricane Sandy had on this region.

Methods

To prepare for the workshop, NACCHO worked with ASPR to:

- Identify and recruit panel presenters;
- Develop a detailed agenda;
- Identify potential participants for the workshop;
- Develop a standardized facilitator guide including questions for breakout discussions; and
- Identify multiple methods of collecting notes and feedback from the workshops sessions including audio recording sessions, recruiting note takers from local Medical Reserve Corps units; and developing detailed note taking guides for participating staff.

To ensure engagement with a variety of HCBS providers from New York, New Jersey and Connecticut, NACCHO reached out to representatives from national HCBS agencies and organizations such as the National Association of States United for Aging and Disabilities (NASUAD)

and the National Association of Area Agencies on Aging (n4a) to conduct informational interviews and identify potential participants. NACCHO also spoke with government officials at the federal, state, and local levels to identify relevant stakeholders for participation in the workshop. Each conversation resulted in additional points of contact. NACCHO contacted approximately 20 organizations resulting in outreach to more than 90 individuals representing HCBS organizations within the tri-state area.

NACCHO also distributed workshop announcements via stakeholder organization networks including the New York City Agency for the Aging and New York City Department of Health and Mental Hygiene. This resulted in outreach to approximately 350 potential invitees via their partner networks. Due to space limitations at the workshop venue, NACCHO monitored registration and scaled outreach efforts accordingly. Following the workshop, NACCHO contacted those organizations that were unable to attend or send representatives to the workshop to gather individual feedback, which is included in the findings of this report.

On June 21, 2016, NACCHO convened a workshop at New York University's Kimmel Center in New York City. Forty individuals from 35 organizations including representatives from HCBS providers in the tri-state area participated. Participants included agencies on aging, disaster case managers, advocacy groups for people with disabilities, home-based nursing services, and LHDs.

The workshop consisted of two panel presentations. The opening session featured federal subject matter experts who presented on the promising practices, emerging challenges and lessons learned related to Hurricane Sandy. The second panel featured state and local subject matter experts who shared their own community-based service experiences related to the storm. After each panel session, NACCHO staff facilitated small group discussions among workshop participants.

During the morning discussion, participants shared challenges and lessons learned related to Hurricane Sandy recovery based on the federal lessons learned. The afternoon breakout discussion focused on successful and innovative practices HCBS providers implemented during Hurricane Sandy recovery, as well as promising practices for improving recovery from future disasters based on examples from their own communities. After each breakout discussion, workshop participants reconvened to report back and continue discussion with the full group.

Jeff Schlegelmilch, Deputy Director of the National Center for Disaster Preparedness at the Earth Institute of Columbia University, facilitated both panel presentations (see Appendix A - Workshop Agenda). He provided an overview of the purpose of the meeting and set expectations for participation in breakout group discussions. NACCHO staff facilitated the breakout group discussions (see Appendix B – Breakout Discussion Questions).

Findings

This report presents the challenges and lessons learned as identified by HCBS providers who attended the workshop, as well as a summary of the innovations and promising practices HCBS providers implemented during Hurricane Sandy in order to foster resilience and recovery for their organizations and clients. A variety of methods were used to synthesize this information including reviewing breakout group discussions captured in notes and flip charts, analyzing audio transcripts of

breakout group discussions, identifying key themes presented in slides from panel presentations, and notes from large group discussion sessions. The goal was to identify common issues experienced by multiple providers, as well as challenges that might be unique to particular geographic areas or organizations. Finally, this report discusses implications of these challenges and potential opportunities to foster resilience and recovery through future activities aimed at integrating HCBS providers and their clients into preparedness planning activities.

General

During the workshop, HCBS providers described challenges they and their clients experienced related to the delivery and receipt of services during Hurricane Sandy. Recovery from the storm was an extensive process that took years and in some communities, is still ongoing. The storm exacerbated underlying social determinants of health including poverty and access to health care. Individuals who were previously independent before the storm, later required increased support and services, resulting in increased demands on HCBS providers. Additionally, HCBS clients faced significant challenges navigating the bureaucracy of the disaster recovery process. A major theme throughout the workshop was the importance of social connectedness of HCBS clients to their neighbors and communities as a critical factor to fostering resilience. Individuals who had support from family, friends, neighbors, or other community members were better able to access social and medical services and disaster recovery resources such as programs for temporary shelter/housing, repairing or rebuilding housing, and behavioral health services. These support systems and connectivity to care enhance community resilience—the ability of communities to withstand, adapt to, and recover from adversity.

Risk Perception and Prior Experience: Hurricane Irene

HCBS providers reported that recent disaster experience with Tropical Storm Irene in 2011 influenced their decision-making in advance of Hurricane Sandy in 2012. Likewise, recent studies demonstrate that although evacuation of residents in high-risk areas is the main way to

reduce hurricane-related morbidity and mortality, evacuation messaging followed by a high-risk/low-impact event, such as Tropical Storm Irene, may contribute to organizations and their clients becoming skeptical of an event's severity.^{7,8}

HCBS providers described their skepticism of some of the warnings issued in advance of Hurricane Sandy, for example:

"We suffered here in New York thinking that something like this couldn't happen here. We see it on the TV, [disasters] happen in the Midwest and in the South, but [we assumed that] it can't happen in New York. And even when Irene happened, all the warnings and nothing happened here. So we thought, okay, they're just making us chickens running around, you know, the sky is falling. But then it really happened, so I think we were all taken by surprise."

While HCBS providers describe having "learned their lesson" from the devastating experience of Hurricane Sandy and their intentions to prepare for the worst in future storms, they conceded that their organizations' and their clients' memories of the storm would likely be short-lived. HCBS providers anticipate that without continued support for disaster preparedness planning, their organizations and clients would likely become complacent about pre-disaster decision making in the future and reluctant to implement disaster risk reduction techniques to mitigate future impacts. Technical assistance, training, engagement, and support for ongoing planning will ensure that disaster preparedness stays at the forefront and HCBS providers can deliver continuity of services to their patients.

Utilities

Disruption of essential utilities was a significant

barrier to ensuring continuity and recovery of HCBS services. An explosion at the 14th Street Consolidated Edison substation resulted in loss of power in lower Manhattan extending from 39th Street and below. Many HCBS providers experienced disruptions to their electricity and telecommunications, in some cases for an extended duration. HCBS providers reported that loss of electricity and telecommunications hindered their ability to activate disaster response plans. Providers that operated in multiple service locations proved more resilient as they were able to adapt and shift services to alternate locations that retained power. For example, a homeless shelter operator in New York City reported that several sites lost power yet they were able to meet increased demand by doubling up homeless families in locations that still had power. Many HCBS providers consolidated operations into fewer sites, making it easier to manage logistics (e.g., fuel and supplies) and ensure continuity of services in the aftermath of Hurricane Sandy.

In light of the disruptions to essential utilities experienced during Hurricane Sandy, HCBS providers discussed options for ensuring access to electricity during future disasters. Many HCBS providers considered purchasing and installing permanent emergency generators for their sites or contracting for portable emergency generators to be stored offsite, accessible in the event of an emergency; however, this approach was considered cost prohibitive. Many agencies could not justify the expense of emergency equipment that may go unused, particularly in the absence of any legal requirement to equip their facilities with generators. There has been some push in recent disasters to require generators in these settings, particularly for areas with high temperatures. HCBS providers described organizational resistance to investing limited funds in emergency equipment rather than activities or resources that bring a direct and guaranteed benefit to their clients. Specifically, some providers reported a lack of organizational support for insuring access to electricity, noting that prolonged power outages are a rare event.

As an alternative to purchasing emergency generators, HCBS organizations prefer to retrofit facilities with "quick-connect" adapters that allow generators to be connected to a building's electrical system. This allows HCBS providers to use leased or borrowed generators, rather than purchasing and maintaining their own equipment. Furthermore,

HCBS providers prefer to prioritize sites for quick connect retrofitting by selecting locations best equipped to house consolidated services in the



event of a disaster. An HCBS provider describes their decision making process for investing in backup power, “I mean, we’ve looked at installing generators of different varieties. The generators themselves are pretty [expensive] capital intensive equipment to just have sitting around for a ‘what if’ [scenario] for a not-for-profit. So we at least tried to create the infrastructure so that if we needed to lease or lend a generator, it could be connected. So we tried to pick out the sites that we would definitely continue to use, the larger sites that we could condense services into, and then make sure that they’re ready for a generator to be plugged in.”

This preparedness strategy allows for minimal site modifications and requires fewer generators in the event of a disaster. Despite these improvements, HCBS providers noted that contracting for just-in-time services, such as portable generators, may be an unreliable approach. In Hurricane Sandy, many organizations contracted with the same providers for generator rentals. One HCBS provider reported that having a relationship with Costco helped to ensure a supply of portable generators. Costco was unable to resell returned generators, so they decided to donate them to the local government, which in turn provided the generators to non-profits and senior housing complexes that had installed quick-connects or that a licensed contractor had inspected.

Communications

During and after the landfall of Hurricane Sandy, telecommunication services were challenging and disruptions presented a significant obstacle to recovery of HCBS services. Local government agencies distributed blast email messages to HCBS providers with updates on emergency preparedness in anticipation of the storm. Upon having their phone services restored after Hurricane Sandy, HCBS providers realized that many of their clients still did not have phone service. Some HCBS providers maintained essential communications through alternate messaging systems (e.g., text messaging, social media messaging, website posts).

One HCBS provider deployed mobile cell phone charging stations for staff. “Our deployment, our creating alternative messaging systems including enabling text messaging and allowing social media messaging in addition to email over phones was very important...the second thing was the deployment specifically of mobile charging stations. We had vans go out that had mobile charging capabilities, and we were pushing email and text messages to all staff as far as the location of those mobile stations in each region.”

The combination of multiple modes of communication and provision of mobile power charging stations facilitated greater communication that providers felt would not have otherwise occurred. Other provider organizations adapted to communication challenges by conducting door-to-door visits (i.e., canvassing) to locate and confirm the safety of clients unreachable by phone.

Additionally, central communication resources contributed to the ability to ensure the safety of HCBS clients. For example, New Jersey maintains a Domestic Violence Central Registry with up-to-date information on all restraining orders entered into the Family Automated Case Tracking System that is available to law enforcement agencies and the Family Court. Under normal circumstances, this registry and an accompanying hotline facilitate enforcement of restraining orders and protection of victims as they move between municipalities and counties in the state. During Hurricane Sandy, when victims of domestic violence needed to relocate due to storm hazards, providers were able to call the hotline where screeners could coordinate relocation to ensure safe and appropriate placement.

Staffing

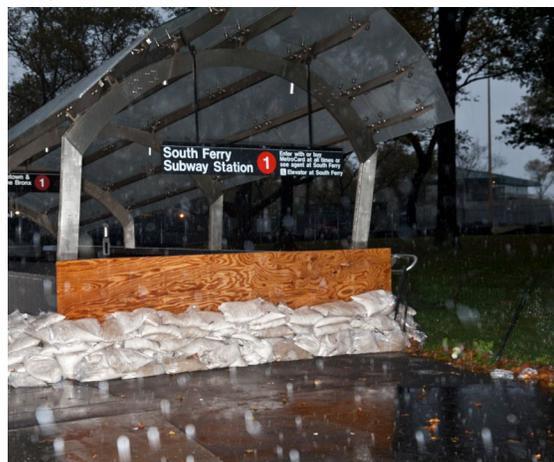
HCBS providers reported staffing challenges. In some cases, staff members affected by the storm were unable to report to work because of damaged infrastructure. HCBS providers stressed the importance of building a work culture that allows for flexibility. They recommended considering flexible schedules during future disasters because it may take longer to reach clients when a disaster has occurred and it may be necessary to triage clients based on their circumstances. Additionally, HCBS providers recommended developing job aid tools for essential tasks to mitigate issues arising from staffing shortages. For example, if a home health worker was unable to reach a client, a job aid with a checklist could enable alternate staff to backfill and ensure continuity of the services. Furthermore, development of job aids and checklists of essential activities by the HCBS provider could allow greater flexibility in staffing assignments and employee cross-training.

HCBS providers noted the importance of behavioral health and worker safety for personnel who experience stressful conditions, personal impacts, and long hours during disaster response. Exposure to disaster may result in distress or need for support. Built-in resources for behavioral health services and on-going worker safety and emergency preparedness training promote greater workforce resilience.

Transportation and Access

Transportation and access to provider sites and client locations were significant challenges for HCBS providers in recovering from Hurricane Sandy. The storm resulted in flooding, downed trees and downed power lines that hindered the ability of both providers and clients to navigate roads, and caused significant damage to the transportation infrastructure. The suspension or closure of public transit such as the Metropolitan Transportation Authority's subway and rail service and the Port Authority of New York and New Jersey's rail service hindered staff's ability to travel to their offices and to client's homes. Suspension of public transit also prevented clients from accessing medical offices and community centers where they normally receive services. This was particularly challenging in New York City where many people do not own private vehicles.

HCBS organizations used passenger vans, normally used for client transport, to shuttle staff to and from work sites. In rare cases, staff walked or biked to work. Some organizations adapted to transportation challenges by having staff report to alternate locations. For example, government agencies in New York City with offices in multiple boroughs instructed employees to report to the location nearest their home. As a result, some program staff were not co-located, which created service delivery challenges. In many instances, staff members lived outside the affected area and were unable to access clients for extended durations.



Essential Personnel or Emergency Responders

Emergency travel restrictions further exacerbated travel and infrastructure challenges created by Hurricane Sandy. In New York City, Long Island, and northern New Jersey, many bridges and tunnels were open only to emergency responders. In many instances, HCBS providers did not have identification or designation as "emergency personnel." Because of this, law enforcement officials often prevented providers from crossing bridges and tunnels or accessing restricted roads.

One HCBS provider described challenges encountered even among staff with credentials:

"...but the biggest [issue reaching patients] was around our nurses not being allowed to—being stopped at roadblocks by the city. And while some of the police would go ahead and let them through with their nurse ID, the mayor's office was intransigent...so we were at the mercy of trying to convince the individual nurses who would try to convince the police officers to let them by to go see their patients."

Additionally, travel restrictions requiring a minimum of three people per vehicle further hindered continuity of client care as home care providers who often travel alone could not gain access to their clients.

The region experienced gasoline shortages, further limiting HCBS providers' ability to deliver services to clients. HCBS providers not designated as essential personnel had difficulty fueling their personal and organizational vehicles to commute to and from work. Consequently, these restrictions interrupted continuity of HCBS services, such as refilling clients' prescription medications or delivery of personal assistant services, and service delivery became increasingly problematic over time, resulting in downstream health impacts for their clients. A home delivered meals provider, for example, experienced difficulty obtaining gasoline for vehicles that contain ovens and refrigerators to maintain the temperature of food. This services ensures the delivery of nutritious meals to maintaining the health and well-being of homebound clients. In some cases, HCBS providers overcame travel restrictions through government authorization to access restricted areas. Police in Suffolk County, Long Island were restricting access to certain areas, for example, but the county executive's office issued a letter to county-employed caseworkers granting access to restricted areas to ensure continuity of client services.

In preparation for future emergencies, it will be necessary for each community to identify HCBS

workers that require restricted travel access to reach their clients and ensure continuity of care. Likewise, providers felt it necessary to grant priority access for fuel to vehicles that deliver essential HCBS services in the event of regional shortages.

Planning and Partnerships

HCBS providers described significant variability in the existence and implementation of emergency plans. When plans did exist, many providers reported difficulty implementing them because of disruptions to power, telecommunications, and transportation. While local government agencies in New York City had Continuity of Operations (COOP) plans, their vendors often did not. In the aftermath of Hurricane Sandy, these agencies were unable to reach vendors in the Rockaways and as a result, could not determine the location and status of clients. In order to sustain essential services, procedures and plans must extend beyond HCBS and local government organizations to include their vendors. In particular, remote access to email, after hours contact information for vendors, and alternate work locations are essential requirements for HCBS providers to continue operations in future disasters.

Planning for redundant communication procedures including even low-tech options is essential to disaster resilient organizations. HCBS providers described the importance of access to hard copies of plans and contact information, as electronic information technology systems are not always accessible or reliable, "...we did this as well and it worked out: hard copy documentation... that our staff went home with—client lists, staff listings, so those who did have access to telephone communication were able to reach out and establish contact. It was the old fashioned way, but it still worked."

Many providers cited the importance of building relationships between local government agencies and community-based organizations before an emergency. During the afternoon plenary session, one presenter provided an example of leveraging pre-existing relationships with law enforcement officials (LEOs) to build internal capacity and meet the needs of community members. During Hurricane Sandy response and recovery, this community in New Jersey used its street outreach teams to prevent "violence and exploitation exacerbated by the storm's impact." While the Social Services Block Grant (SSBG) funding for the

outreach teams program had ended prior to Hurricane Sandy, the partnerships established between LEOs and social service providers remained intact, and the outreach teams were successfully activated to support the community's disaster response activities.

In addition to developing organizational plans and partnering with outside organizations, providers also shared examples of agencies preparing with their individual clients. For example, the New York State Office of Children and Family Services enrolled approximately 3,500 children and adolescents in their Bridges to Health (B2H) program.

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This program is designed to provide children in foster care who have significant mental health, developmental disabilities, or health care needs with services to help them live in a home or community-based setting.⁹

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In addition to the 14 services provided to foster children enrolled in B2H, the program offers preparedness information and education to the clients and their families. During Hurricane Sandy, the value and impact of B2H was clear. At the time of the storm there were approximately 3,500 children and adolescents participating in the B2H program. B2H was able to account for every participant, each of whom had an individual preparedness plan for the storm.

Because the B2H program places an emphasis on maintaining emergency plans and contact information, they were able to quickly assess the status of their clients and react accordingly. This example demonstrates the importance of pre-planning with clients in two ways. First, in maintaining contact with their clients, B2H was able to address any needs that might arise. Second, once B2H established the safety and security of their clients, they were able to evaluate their own response efforts and make informed adjustments to their actions, potentially increasing their reach and impact within the community.

Web-based Client Database & Pre-emergency Check-in

In advance of Hurricane Sandy, many HCBS providers called their high-risk clients to determine whether they had adequate supplies of medications and to assess their individual storm plans (i.e., was the client planning to evacuate to a family member's house or public shelter, or did the client plan to shelter-in-place?). When clients did not have a plan in place, the HCBS providers helped them develop an emergency plan for the storm.

Pre-landfall, the HCBS providers developed plans to ensure that high-risk aging services clients received essential services. The New York City Department for the Aging requires the use of a web-based client database by all agencies it funds to provide case management and caregiver services for older adults. Prior to Hurricane Sandy, these providers updated the client database with the following types of information: emergency contacts; medical conditions and needs (e.g., dialysis two times per week, Foley catheter), medications, durable medical equipment (e.g., oxygen tank, power dependent medical equipment); as well as home conditions (e.g., presence/absence of an air conditioner). This level of detail helped to pre-identify high-risk HCBS clients whose health and wellbeing might be at greatest risk. For example, clients may be at-risk during a heat emergency because they do not have an air conditioner, but this risk factor would not apply when preparing for a snowstorm.

In Suffolk County Long Island, there is an emergency registry for at-risk individuals who may need special assistance during a disaster, however, it is not widely used. Providers noted that such databases require continual maintenance to be useful. Instead, HCBS organizations make use of existing client database information for assessing client risk in advance of an emergency. Additionally, providers reported that while pre-emergency check-ins were not unique to Hurricane Sandy, it is crucial to conduct these assessments before and after each emergency and to assess clients' risk in different circumstances. For HCBS providers affiliated with the New York City Department of Aging, they can search the client database by flood zone to identify clients who live in areas ordered to evacuate or at great risk of flooding.

Another important consideration of HCBS providers for clients with access and functional needs, and in particular clients with mobility disabilities, is whether they live in a high-rise apartment building where power loss could disrupt elevator service. It is important to record housing type in client databases, and to consider this factor in client risk assessments and in developing risk communication for clients about their emergency plans, particularly when clients plan to shelter-in-place. Since Hurricane Sandy, some HCBS providers reported developing relationships with building captains. While local building codes vary on definitions of "high-rise buildings," these floor or building captains are typically high-rise residents volunteers trained in fire safety and evacuation. They can serve as points of communication between residents with access and functional needs and the HCBS organizations. In the event that HCBS providers are unable to reach clients in these developments, they plan to rely on building captains to check on clients in-person.

One HCBS provider describes adding high-rise building captains to their client risk assessment procedures, "...and so in addition to calling the clients who were frail and vulnerable, they also have building captains in each building. So I've developed relationships with the building captains, and I called them before various impending disasters and said, can you check on the seniors in your building if something happens and we can't get there? So that makes it a little more manageable. They may have to check on ten or fifteen or twenty people or more because it's a thousand seniors in the development."

Emergency Shelters

HCBS providers reported challenges with the accessibility of facilities used as public emergency shelters during Hurricane Sandy. Some jurisdictions used schools as emergency shelters, only to realize that the schools had blocked internet access to prevent students from surfing the web during class, which restricted the HCBS providers' ability to communicate with shelter managers and staff. Another challenge was the lack of accessible shelters for HCBS clients with mobility disabilities (e.g., buildings lacked ramps or adequate turning radius space) and the resulting non-compliance with the requirements of Americans with Disabilities Act (ADA). As described in the ADA Best Practices Tool Kit for State and Local Governments,¹⁰ facilities selected to be emergency shelters must comply with ADA to ensure equal access of the shelter program for people with disabilities.



Additionally, some HCBS providers realized during Hurricane Sandy that shelter environments may exacerbate conditions for some people with disabilities. Because of this lesson learned, HCBS providers report advanced planning should occur, when possible, for extra rooms within shelters that can serve as a quiet space for individuals with developmental disabilities or cognitive disorders. One HCBS provider describes emergency preparedness coordination to accommodate clients with sensory disabilities, "We're making sure to survey [shelter sites] to make sure they're accessible, but also have extra rooms so that if people come in

with cognitive issues, developmental disabilities, are sensitive to light, noise, we can offer them a quieter room to be in that might, you know, keep people calm...the sense is, you know, you're going to have families coming in with a child with special needs... and they're worried about their behavior and disrupting and getting kicked out of the shelter. So if we can just even have optional rooms at the ready, ideally. It's not always going happen, but that's one of the things we're definitely planning for."

In addition to ensuring accessibility required by the ADA, communities should plan to accommodate the needs of people with disabilities and others with access and functional needs when selecting or designing shelters or planning space use at shelters. The American Red Cross CMIST worksheet provides considerations of scenarios for access in functional needs in a shelter setting.¹¹

Another challenge for HCBS providers was balancing client confidentiality with the collection of health information. Many shelters did not require shelter residents to register or provide personal information because they did not want to deter people from seeking shelter. Additionally, there were restrictions on sharing shelter residents information between the American Red Cross, the Federal Emergency Management Agency (FEMA), local government agencies, and providers. Consequently, HCBS providers reported that it was difficult to determine and address the health needs of shelter residents. For example, a provider might not know if children and families staying in a shelter were under the supervision of Child Protective Services, and would not know to contact a caseworker. Conversely, HCBS providers stressed the need to ensure confidentiality of shelter residents, citing domestic violence victims as an example. Another confidentiality issue arose for individuals with HIV/AIDS who wanted or needed to stay in medical shelters because of the availability of refrigeration for their medications. In some instances, shelter operators did not perceive these clients as needing special medical services because they did not appear sick or disabled. It is important to note; however, that during a declared disaster or public health emergency some aspects of the HIPPA Privacy Rule are waived to allow patient information to be shared to ensure continuity of care in disaster relief efforts.¹²

In some of the most devastated areas such as the south shore of Staten Island, Hurricane Sandy destroyed residential group homes and HCBS clients

were unable to return. Government agencies faced the challenge of trying to quickly relocate displaced clients, an endeavor that was complicated by an existing shortage of supportive housing for people with disabilities (such as physical or developmental disabilities or chronic mental illness). In some instances, it was necessary to provide clients with temporary accommodations in one facility until they found permanent placement in an appropriate residences. Although there were hotel programs, the number of available rooms in Brooklyn and Staten Island was extremely limited due to demand from both displaced residents and emergency workers. Moreover, hotels were only a temporary solution. In New York City, finding permanent housing was particularly hard because of the low vacancy rate.

Funding – Contracting, Grants, and Reimbursement

During Hurricane Sandy, many HCBS providers delivered services beyond the scope of their contract, not knowing whether they would receive reimbursement. For example, home delivered meal programs provided extra meals to people who were not in their databases (i.e., they were not registered clients), but were clearly in need of food. While the types of services provided met their organizations mission, HCBS providers were worried they would not receive compensation for additional services or expenditures incurred while responding to emergent needs encountered during Hurricane Sandy.

Additionally, HCBS providers described lack of clarity on compensation for altered services or scope of care. For example, it was necessary for some home care attendants to shelter-in-place with clients during Hurricane Sandy to ensure continuity of care during and in the immediate aftermath of the storm. HCBS providers reported that policies limited compensation for attendants who remained onsite with clients during the storm. Domestic live-in employees typically receive a flat rate, and existing policies regulating 24-hour care prevented HCBS agencies from paying these staff overtime. One HCBS organization adapted to the challenge of uncompensated services by applying for a waiver to approve increased level of care. Based on their experience in Hurricane Sandy, the provider recommended that as part of their emergency planning, HCBS providers develop a "waiver playbook" of template emergency waivers. These template waivers would be similar to pre-

written disaster declarations or orders of succession in a COOP plan. Playbooks would consist of waivers HCBS providers are most likely to request, as well as just-in-time instructions on how to make the request and submit the form. Providers would modify, complete, and immediately submit these waivers to authorizing agencies in the event of a disaster to ensure both compensation and continuity of client care.

One HCBS organization reported that they instructed all of their clinicians to photographically document the home and surrounding environment of clients they visited.

“... we instructed all of our clinicians and anybody who went out to a home, to a location to do photographic documentation on their [smart] phones of the outside environment, of the home, et cetera, to document the physical conditions: the water, the disruption of the home...and it helped, evidently, significantly in gaining rapid authorization for extra service hours from managed care organizations. Evidently [the photographs] just facilitated that phenomenally because you had a picture with it. ‘Here’s the situation. Here’s why we need the extra services.’ And I believe we made those—I’m virtually certain we made those available to our patients and families to help them in documenting damage.”

In this instance, having documentation of the physical conditions and damage to clients’ homes facilitated rapid authorization of extended services. Clients were also able to use the photographs for their own insurance purposes.

A lesson HCBS providers learned was that recovery from a major disaster is a long process. It took significantly longer than expected for their

organizations and their clients to recover from Hurricane Sandy. Following Hurricane Sandy, HCBS providers were eligible for supplemental funding through the Hurricane Sandy SSBG Program to support state efforts to address social services, health, and mental health services recovery needs of disaster survivors, and the repair, renovation and rebuilding of health care facilities (including mental health facilities), child care facilities, and other social services facilities damaged or destroyed by the disaster. During the workshop, however, HCBS providers reported that the 2-year supplemental funding period of the Hurricane Sandy SSBG Program was too short given the time it took to recover. The duration of the SSBG, as opposed to the need, drove grant award decision-making. In some instances, local government organizations wanted to award grants to proposed initiatives they believed would be the most effective, yet exceeded the allotted duration for completion.

Federal Assistance

With the exception of FEMA, other federal government agencies responsible for disaster preparedness, response, and recovery activities were unknown to communities affected by Hurricane Sandy. HCBS providers described the experience of many federal agencies as “parachuting” into the community during Hurricane Sandy. HCBS providers lacked an awareness of federal disaster resources or how to request available support. Similarly, local government organizations were not aware of all of the federal assets operating within their jurisdiction. In one community, a Disaster Medical Assistance Team was present, but never checked in with the county emergency operations center. Even individuals who had been involved in prior emergency response, such as the September 11 attack of the World Trade Center, said they were uncertain if a disaster were to occur today, whether these federal organizations could be relied on to provide disaster assistance. One provider who works with older adults said, “It seemed magical when the federal agencies other than FEMA came in and helped—I don’t even know who they were. FEMA and the National Guard—that’s who we know and the other disaster organizations, I don’t know who they are. They’re not a presence in the community that I work in.” Others noted that there was no central repository of agencies involved in the response and recovery; consequently, they spent a significant amount of time trying to determine who was working in the community.



Response and Recovery Planning

HCBS providers identified a lack of comprehensive response and recovery plans to many of the recurring challenges in providing services to their clients following Hurricane Sandy. Providers stated that their staff lacked expertise in developing emergency plans. Addressing this gap will require a multi-tiered approach including the provision of technical assistance in the development of planning documents, development of a resource repository for existing planning documents; sample planning templates, and guidance for the development of comprehensive plans.

Administrative preparedness is another key need and is defined as the process of ensuring the appropriate integration of fiscal, legal, and administrative authorities and practices that govern funding, procurement, contracting, and hiring into all stages of emergency preparedness and response. For HCBS organizations, administrative preparedness includes the identification of waivers that would allow for administrative flexibility in meeting funding organizations regulations/requirements. Examples of administrative preparedness tools and resources include:

- A standard intake screening tool that could facilitate rapid assessment of clients across organizations. Provider organizations could use this tool to reduce or possibly eliminate duplicative procedures.
- Identification of a local authority and development of documentation designating emergency responder/essential personnel that would allow HCBS providers access to clients in restricted areas.

Individual Preparedness

While response and recovery planning will dictate organizational response, efforts to support clients of HCBS organizations to assure their personal preparedness are also necessary. HCBS organizations can play a vital role in assisting their clients to be prepared in case of an event and thereby, increasing community resilience. Examples of this include providing early services to existing clients for events with advanced notice, strategic pre-positioning of response resources, and providing preparedness education to clients during regular in-home visits.

In addition, HCBS organizations could develop a pre-screening template to check in with their most vulnerable clients prior to an emergency. Providers would ensure that clients have emergency kits (including medications, food, and water) and emergency plans (whether or not they plan to evacuate, where they will go, whether it is accessible, or if shelter in place, is there was a friend or family member available to check in on them). Additionally, it may be necessary to have waivers in a disaster that would allow clients to refill their prescriptions at a local pharmacy or mobile pharmacy rather than going through insurance to obtain their regular prescriptions by mail.

Coordination

Another overarching theme expressed by HCBS providers focused on their involvement in community preparedness planning and response activities. For many HCBS organizations, simply “getting a seat at the table” with emergency management was a major obstacle. Direct involvement in the process of preparedness planning can produce many ancillary benefits. It can improve the ability of HCBS providers to respond and ensure continuity of care for their clients. It can also improve the overall community-wide response by mitigating long-term health care impacts of the disaster affected community, thereby facilitate better long-term recovery outcomes. In order to address this gap, public health and emergency management officials should be encouraged to recognize and engage with HCBS agencies as part of their planning efforts.

There are two primary areas where developing partnerships will benefit both HCBS providers and the wider emergency response community. The first involves building relationships with

other responding agencies to integrate HCBS providers into a community-wide response. This could be accomplished through engaging with local healthcare coalitions, which are groups of local healthcare and responder organizations that collaborate to prepare for and respond to emergencies. It could also be accomplished through HCBS provider representation in Emergency Support Function 8 (ESF-8) workgroups, which coordinate the public health and medical response system for their local jurisdictions all-hazards planning. Another approach could focus on building a network among the HCBS providers themselves. Many HCBS providers pointed to a lack of coordination across their agencies as an obstacle to reaching their clients during the response to Hurricane Sandy. Absent this provider-level coordination, there was no way to assess potentially redundant efforts, or to determine if certain client groups were inadvertently overlooked in their outreach. Both examples indicate the importance of partnerships in emergency response as a means to improve coordinated response efforts and enhance health situational awareness through the sharing of critical information.

Coordination among HCBS organizations would also be helpful in identifying their most vulnerable clients and urgency of need in an event. While some communities support development of registries, others have found that they are difficult and costly to maintain. Privacy remains an issue and it is difficult to operationalize the information in the event of a disaster. HCBS providers are in the best position to inform response activities related to their clients as they regularly maintain health situational awareness of their clients' specific needs.

Conclusion

It is important to note that as of the date of this report, the Centers for Medicare and Medicaid Services (CMS) has finalized a rule to establish consistent emergency preparedness requirements for healthcare providers participating in Medicare and Medicaid, to increase client safety during emergencies, and to establish a more coordinated response to natural and man-made disasters. For some HCBS providers, the rule will result in increased emergency preparedness planning and coordination with federal, state, tribal, regional, and local emergency preparedness systems to ensure that facilities are adequately prepared to

meet the needs of their clients during disasters and emergency situations. This rule applies to the following provider types:

- Hospitals
- Religious Nonmedical Health Care Institutions (RNHCIs)
- Ambulatory Surgical Centers (ASCs)
- Hospices
- Psychiatric Residential Treatment Facilities (PRTFs)
- All-Inclusive Care for the Elderly (PACE)
- Transplant Centers
- Long-Term Care (LTC) Facilities
- Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)
- Home Health Agencies (HHAs)
- Comprehensive Outpatient Rehabilitation Facilities (CORFs)
- Critical Access Hospitals (CAHs)
- Clinics, Rehabilitation Agencies, and Public Health Agencies as Providers of Outpatient Physical Therapy and Speech-Language Pathology Services
- Community Mental Health Centers (CMHCs)
- Organ Procurement Organizations (OPOs)
- Rural Health Clinics (RHCs) and Federally Qualified Health Centers (FQHCs)
- End-Stage Renal Disease (ESRD) Facilities

While many of these providers are clinical, several of them fall under the previously stated definition of HCBS provider. Because of this, involvement and inclusion of HCBS organizations and agencies in community preparedness planning is more important than ever before.

The information contained in this report demonstrates a need among HCBS providers for support and assistance related to disaster preparedness, response, and recovery planning efforts. The new CMS rule spurs this need into action, compelling HCBS organizations to take steps to improve emergency preparedness planning and coordination. This creates a unique opportunity to engage HCBS providers in community preparedness planning activities to begin addressing gaps in preparedness for these organizations and their clients.

Appendix A - Workshop Agenda

Hurricane Sandy Recovery Workshop: Lessons Learned and Promising Practices for Home and Community-Based Service Providers

TIME (EST)	Event (EST)
09:30 AM-10:00 AM	Registration
10:00 AM-10:15 AM	Welcome/Opening Remarks Laura Biesiadecki, National Association of County and City Health Officials (NACCHO)
10:15 AM-11:15 PM	Discussion on Promising Practices Emerging From Challenges and Lessons Learned Cheryl Levine, HHS/ASPR/OPP/ABC; Kristen Finne, HHS/ASPR/OPP; Natalie Grant, HHS/ASPR/OEM; Murad Raheem, HHS/ASPR/OEM; Kathleen Otte, ACL, Region 2 The purpose of this panel is to set the stage for the morning breakout discussion, which will focus on challenges faced during the response and recover from Hurricane Sandy. Panel members will discuss challenges experienced during Hurricane Sandy and opportunities to foster resilience from the federal perspective. At the end of this panel, the audience will have a better understanding of recovery efforts in the tri state area.
11:15 AM-11:30 AM	Breakout Session 1 Kickoff Jeff Schlegelmilch, National Center for Disaster Preparedness, Columbia University
11:30 AM-12:30 PM	Breakout 1: Challenges and Lessons Learned Attendees will discuss their experiences as home and community-based health service providers during Hurricane Sandy and lessons learned regarding what contributed to or hindered their recovery efforts. Each breakout group should identify a speaker to report back a summary of their discussion to the entire group.
12:30 PM-1:00 PM	Breakout 1 Report Out
1:00 PM-1:45 PM	Lunch
1:45 PM-2:45 PM	What Made the Difference: Community-Level Promising Practices After the Storm LaTasha Holmes, New Jersey Department of Children and Families Michele DeLuca, City of Norwalk Office of Emergency Management Hunter Arton, Norwalk Redevelopment Agency Karol Tapias, LiveOn NY Panel members will discuss promising practices that emerged during the response to Hurricane Sandy and opportunities to foster resilience from the social services perspective. At the end of this this panel, participants will be able to describe innovations in recovery that can help to improve resilience and minimize disruption in services after a disaster.
2:45 PM-3:00 PM	Breakout Session 2 Kickoff Jeff Schlegelmilch, National Center for Disaster Preparedness, Columbia University
3:00 PM-4:00 PM	Breakout 2: Innovations and Promising Practices Attendees will discuss promising practices that they employed during Hurricane Sandy (or that they have since determined could be used) to ensure continuity of home and community-based health services in future emergencies. Each breakout group should identify a speaker to report back a summary of their discussion to the entire group.
4:00 PM-4:45 PM	Breakout 2 Report Out
4:45 PM-5:00 PM	Closing Remarks Sally Phillips, Office of the Assistant Secretary for Preparedness and Response HHS Laura Biesiadecki, National Association of County and City Health Officials (NACCHO)

Appendix B - Workshop Discussion Questions

Hurricane Sandy Recovery Workshop: Lessons Learned and Promising Practices for Home and Community-Based Service Providers

Breakout Session 1: Challenges and Lessons Learned

Topic

This breakout session will focus on challenges and lessons learned related to the role of HCBS providers in Hurricane Sandy Recovery.

Rational Aim

To learn from participants what specific challenges they faced and the level of impact these challenges had on their ability to provide services to their clients.

Experiential Aim

To give participants a forum to share their experiences and learn from the experiences of others. These discussions may also inform the decision-making abilities of participants during future recovery planning efforts.

Questions

1. What are some of the challenges your organization or your clients experienced related to delivery and receipt of services?
2. What were some of the challenges your organization faced in trying to minimize disruptions to your services leading up to, during, and after Hurricane Sandy?
3. Given that different areas had evacuation orders, did this further challenge your service delivery and connectivity to your clients? If so, how?
4. Overall, what was the biggest challenge your organization and your clients faced as you worked to recover and get back to normal?
5. What were the major lessons learned that you wish you would have known and included in your emergency preparedness plans for your organization prior to Hurricane Sandy?
6. What types of immediate and/or longer term resources (tools, guidance, and/or funding), support (i.e. staffing, supplies, gas, etc.) or communications would have helped your efforts to continue service delivery during Hurricane Sandy and as you recovered back to normal?
7. What would have been the optimal timeline for receiving those immediate and longer term resources?
8. What are the major lessons learned regarding your client's needs and emergency preparedness practices during and following Hurricane Sandy?
9. If there was one thing you could have known before Hurricane Sandy to help your organization and clients, what would it be?

Breakout Session 2: Promising Practices and Successes

Topic

This breakout session will focus on promising practices and successes related to Hurricane Sandy Recovery.

Rational Aim

To learn from participants what specific promising practices were implemented and the implications of these practices on their ability to provide services to their clients. We are also looking to collect promising practices, innovative tools, and other relevant resources that are generalizable to other organizations across the country.

Experiential Aim

To give participants a forum to share their experiences and learn from the experiences of others. These discussions may also inform the decision-making abilities of participants during future recovery planning efforts. A second aim is to facilitate the sharing of promising practices and tools among workshop participants and beyond.

Questions

1. What are some examples of innovative activities and/or promising practices your organization used to manage and overcome the challenges following Hurricane Sandy, and to the best of your ability, to ensure continuity of services?
2. Were there any specific emergency preparedness actions taken prior to Hurricane Sandy and or as a result of prior disaster experience that you believe informed your approach to maintaining services for your clients?
3. Were there specific tools, resources, or policy flexibilities that helped address your client's needs that other organizations or jurisdictions should implement?
4. Were there actions that your clients took that may have enhanced their resilience during Hurricane Sandy?
5. Are there policy or emergency preparedness changes that could be made to better inform or foster your ability to serve your clients in future disaster?

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