



CASE STUDY: CLINTON COUNTY HEALTH DEPARTMENT

Inclusion of People with Intellectual Disabilities in a More Inclusive Emergency Response Plan

People with intellectual disabilities often face barriers to accessing public health promotion and protection activities, making them particularly vulnerable to preventable disease and injury. In turn, practicing inclusive health not only provides more equitable access to public health resources, but also leads to improved health outcomes and helps health departments meet and maintain a variety of public health accreditation standards. The Public Health Accreditation Board, with funding support and in partnership with Special Olympics International, presents this short case study for the purpose of exploring how the Clinton County Health Department in Plattsburgh, New York, engaged local advocates and community members in adopting inclusive preparedness competencies and created a more inclusive emergency response plan. Clinton County Health Department is among a handful of state and local health departments across the nation who are advancing inclusive health for people with intellectual disabilities.

THE PROBLEM

Research shows that people with intellectual disabilities face disproportionate risks in the event of a public health emergency or disaster.¹ People with intellectual disabilities are more likely to be unprepared or left behind during a disaster, and federal, state and local emergency response plans often overlook the needs of this population.² In Plattsburgh, New York, the Clinton County Health Department set out to shift that dynamic, engaging local advocates and community members in adopting inclusive preparedness competencies and creating a more inclusive emergency response plan. One way to address those gaps is to ensure equitable access to mainstream systems and services.

BACKGROUND

Every year, like most health departments, the Clinton County Health Department in upstate New York participates in emergency preparedness drills as part of nationwide efforts to keep public health systems ready for disasters and disease outbreaks. The agency's full-scale community drills test a range of emergency response skills, but each year, the state challenges local health officials to stress and test a particular capacity. About four years ago, that challenge focused on making sure health departments effectively included and served residents with intellectual disabilities during a public health emergency.

"You really don't know how someone with an intellectual disability will navigate your flow path or understand your messaging until you test it in real life," said Margaret Searing, RN, Quality Coordinator at the Clinton County Health Department. "It's been a huge learning experience for us."

¹ Journal of Policy and Practice in Intellectual Disabilities:
<https://pdfs.semanticscholar.org/3034/3b3a7912c3b0443b900362bc6c26eea692b9.pdf>

² National Association of County and City Health Officials: http://nacchopreparedness.org/wp-content/uploads/2016/09/16_EH_Emergency-Planning-PPI-w-Disabilities_FactSheet.pdf

Like so many activities in public health, emergency response depends heavily on community engagement and partnership. So naturally, Margaret LaBombard, the Public Health Emergency Preparedness Coordinator, along with her colleagues, sought out a local partner to help make their practices more inclusive — ideally, a partner already positioned as a trusted provider for people with intellectual disabilities. Fortunately, they didn't have to search far, as the health department already had a working partnership with Plattsburgh's Advocacy and Resource Center (ARC), which serves hundreds of residents with intellectual and developmental disabilities and advocates for their active participation in the community. The partnership was an ideal fit for both agencies: preparedness staff could leverage local expertise in creating and testing inclusive response plans, and ARC could use the opportunity to beef up emergency skills among its own health staff.

"Partnership-building has been a longtime strength of our health department," Searing said. "In fact, it's one of our greatest strengths and it's frequently the way we get work done in small, rural health agencies like ours ... Public health work is everybody's work."

To meet the state's inclusion challenge, the health department's Public Health Emergency Preparedness and Response (PHEPR) program set a specific goal for its medical countermeasure response: over the course of the grant period, eliminate separate, often-slower, lines for people with intellectual disabilities.

"The whole point was trying to find a way to be more inclusive of people with intellectual and physical disabilities and to have everyone go through the same line and feel included in the response," Searing said. "Full inclusion was the goal. Taking incremental steps with each new community drill (there were three during the period) was the method."

In the event of a bioterrorism attack or disease outbreak, it will be up to local public health workers to reach residents with critical information and rapidly organize and disseminate medical countermeasures such as vaccines and other medical prophylactics. At the same time, research shows that people with intellectual disabilities face disproportionate risks in disaster situationsⁱ, are more likely to be unprepared or left behind during a disaster, and that federal and state emergency response plans often overlook the accommodations people with intellectual disabilities may need.ⁱⁱ One way to address those gaps is to ensure equitable access to mainstream systems and services.

SOLUTION

During the 2014-15 PHEPR grant year, the Clinton County Health Department set out to advance inclusion in its emergency preparedness and response activities. The particular goal, with ARC's help, was to design and conduct a medical countermeasure drill that integrated the needs of people with intellectual disabilities and enabled them to access emergency services alongside their fellow community members and without compromising overall response efficiency. PHEPR staff partnered with ARC and its clients throughout the process, from planning to implementation to evaluation. Among the first steps, organizers identified barriers that people with intellectual disabilities would likely face during a medical countermeasure event, such as hard-to-understand signage or landscape features that impede physical access to an intervention site.

For example, Searing said PHEPR staff, assisted by the department's health Literacy Committee, revamped the signs they use to help people navigate a medical countermeasure event, which in real life could be quite chaotic. The new signs were bigger and easier to spot, easier to comprehend, and used universally known symbols and graphics, which Searing noted is also helpful for residents who speak languages other than English — a spillover effect that public health workers typically refer to as a "co-benefit." Because many people with intellectual disabilities also live with a physical disability, the inclusion challenge pushed PHEPR staff and partners to re-survey the drill site's physical landscape and ensure people of all abilities could safely access the services inside.

Throughout the planning process, Searing said staff researched existing standards for guidance on how to integrate inclusive principles into overarching response plans, as opposed to adopting a separate set of principles just for residents with intellectual disabilities. An example of such guidance is the Humanitarian Inclusion Standards, which global relief organizations such as CBM International and the International Federation of Red Cross developed to make sure older people and people with disabilities are effectively included in humanitarian and relief actions.

“When you insert (inclusion principles) into your working infrastructure, it means that even if we experience a turnover in staff, the remaining infrastructure will continue to support inclusion,” Searing noted. Turnover in the PHEPR Coordinator position during this period tested this assertion and proved it correct.

To test out the newly inclusive response plan, PHEPR staff worked with ARC to invite residents with intellectual disabilities to participate as actors in the drill, which typically takes place at a location big enough to quickly accommodate and serve a large percentage of the community, such as a school or community center. Searing said a number of ARC’s clients agreed to participate with the full understanding that the drill was not in response to a real emergency. The overall goal of the drill: to deliver countermeasure medications to as many people as possible in a short amount of time, typically less than two days, while still identifying and effectively serving especially vulnerable residents, such as people with disabilities, pregnant women and those with compromised immune systems. The inclusive drill eliminated separate lines for people with intellectual disabilities, but organizers did set up a table for people who still required extra help or had extra questions so that the main distribution line could keep up a quick pace.

The inclusive drill was a success, Searing said, with responders effectively able to integrate and meet the needs of people with intellectual disabilities within the main distribution line. People with intellectual disabilities who participated in the drill also helped evaluate the exercise, with many reporting that they enjoyed the experience and the opportunity to participate in an important community service.

“They were volunteering their time and themselves to come and help us out,” Searing said. “It’s been a mutually beneficial experience.”

The inclusive drill not only beefed up the health department’s emergency skills, but ARC’s as well. Searing said PHEPR staff also provided training for ARC nurses, who then participated in one of the medical countermeasure exercises. The co-benefit? In the event of a real emergency, ARC is better able to protect its own clients by conducting a closed POD without having to rely solely on the health department, which would likely be inundated with requests in a real-life public health emergency.

Searing said the health department continues to engage ARC and its clients in its emergency preparedness activities. And in fact, she said the inclusion challenge has pushed the agency as a whole to further expand its understanding of the cultural competencies needed to better engage and serve people with intellectual disabilities.

“By inserting inclusion in all policies, it helps move staff to a place where they’re more likely to see this as the normal way of doing business. We bake it into the cake — make it a part of who we are,” Searing said. “We’re a small health department and we don’t have a lot of resources, so the more we can connect the dots and find commonalities, the better we’re able to deliver our services in a quality way.”

CHALLENGES

As is the case with designing and implementing any community health program, there were a number of challenges to overcome, such as:

- **People with intellectual disabilities face disproportionate risks** in disaster situations and are more likely to be unprepared or left behind during a disaster, making them particularly vulnerable to preventable disease and injury.
- **State and federal emergency response plans** often overlook the accommodations people with intellectual disabilities may need.
- **Designing and conducting medical countermeasure drills** that integrate the needs of people with intellectual disabilities alongside their fellow community members, without compromising overall response efficiency, can be challenging.
- **Barriers must be confronted**, such as landscape features that impede physical access to an intervention site, or signs that are not easy to spot or comprehend.
- **Understanding the cultural competencies** needed to better engage and serve people with intellectual disabilities involves a learning curve.
- **Inclusion in all policies** is a goal that takes time to reach, but in the end helps move staff to a place where they are more likely to see inclusion as the normal way of doing business.

LESSONS LEARNED

Best practices for engaging local advocates and community members in adopting inclusive preparedness competencies and creating a more inclusive emergency response plan include:

- **Engage trusted partners.** Engaging in partnerships, especially with local partners who are already positioned in the community as trusted providers for people with intellectual disabilities, is a key best practice for adopting an inclusive emergency response plan.
- **Think “mainstream.”** Federal and state emergency response plans often overlook the accommodations people with intellectual disabilities may need. One way to address these gaps is to ensure equitable access to mainstream systems and services; this is a core tenet of inclusive health.
- **Drills should be inclusive.** When holding drills, invite residents with intellectual disabilities to participate as actors, and give them the opportunity to evaluate the exercise afterwards.
- **Ensure sustainability.** “Bake” inclusion principles into your health department’s infrastructure to ensure that these efforts continue even in the face of staff (or champion) turnover or loss of funding.
- **Focus on health literacy.** Hard-to-understand signage can impede access to an intervention site. Ensure that signs are easy to comprehend and use universally known symbols and graphics.

ADDITIONAL RESOURCES

Guidance on Integrating People with Access and Functional Needs into Disaster Preparedness Planning for States and Local Governments/U.S. Department of Health and Human Services

www.phe.gov/Preparedness/planning/abc/Pages/afn-guidance.aspx

Emergency Planning for People with Disabilities: A Legal Perspective

National Association of County and City Health Officials

http://nacchopreparedness.org/wp-content/uploads/2016/09/16_EH_Emergency-Planning-PPI-w-Disabilities_FactSheet.pdf

Preparing for Disaster for People with Disabilities and Other Special Needs

Federal Emergency Management Agency

www.fema.gov/media-library-data/20130726-1445-20490-6732/fema_476.pdf

Humanitarian Inclusion Standards

www.cbm.org/Humanitarian-Inclusion-Standards--535440.php

Disaster Safety for People with Disabilities

Red Cross

www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html

QUESTIONS?

If you are interested in learning more about this program or how you can apply some lessons learned to your own organization, please contact Margaret C. Searing at (518) 565-4840, or via email at Margaret.Searing@ClintonCountyGov.com.

ⁱ Journal of Policy and Practice in Intellectual Disabilities:

<https://pdfs.semanticscholar.org/3034/3b3a7912c3b0443b900362bc6c26eea692b9.pdf>

ⁱⁱ National Association of County and City Health Officials: http://nacchopreparedness.org/wp-content/uploads/2016/09/16_EH_Emergency-Planning-PPI-w-Disabilities_FactSheet.pdf