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Best Practices and Lessons Learned From the Public Health Disability Specialists Program: Addressing the Needs of People With Disabilities During COVID-19

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Abstract

Context: The Association of State and Territorial Health Officials (ASTHO) and the National Association of County and City Health Officials (NACCHO) applied funding issued by the US Centers for Disease Control and Prevention (CDC) to implement the Public Health Disability Specialists Program, part of a project to address the needs of people with disabilities during the COVID-19 pandemic. Disability specialists (subject matter experts) were embedded within state, territorial, and city/county health departments to help ensure disability inclusion in emergency planning, mitigation, and recovery efforts.

Objective: To evaluate the success of the Disability Specialists Program in improving emergency response planning, mitigation, and recovery efforts for people with disabilities within participating jurisdictions.

Design: Disability specialists worked with their assigned jurisdictions to conduct standardized baseline health department needs assessments to identify existing gaps and inform development and implementation of improvement plans. CDC, ASTHO, and NACCHO implemented a mixed methods framework to evaluate specialists' success.

Setting: State, territorial, and local health departments across 28 jurisdictions between January 2021 and July 2022.

Main Outcome Measures: Average number of categories of gaps addressed and qualitative documentation of strategies, barriers, and promising practices.

Results: Specialists identified 1010 gaps (approximately 36 per jurisdiction) across eight needs assessment categories, most related to mitigation, recovery, resilience, and sustainability efforts ($n = 213$) and communication ($n = 193$). Specialists addressed an average of three categories of gaps identified; common focus areas included equitable COVID-19 vaccine distribution and accessible communications. Specialists commonly mentioned barriers related to limited health agency capacity (eg, resources) and community mistrust. Promising practices to address barriers included sharing best practices through peer-to-peer networks and building and strengthening partnerships between health departments and the disability community.

Conclusions: Embedding disability specialists within state, territorial, and local health departments improved jurisdictional ability to meet evolving public health needs for the entire community, including people with disabilities.

Keywords

disability inclusion; emergency preparedness; health equity

Introduction

People with disabilities have historically experienced disproportionate negative impacts from disasters compared to people without disabilities.¹ Disparities are exacerbated by increased negative influence of social determinants,² such as poverty³ and stigma,¹ and inaccessible information and resources.^{4,5} The COVID-19 pandemic has been no exception.⁶ Despite early calls for a disability inclusive response to COVID-19,⁷⁻¹⁰ people with disabilities

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often remain overlooked.¹¹ Inaccessible communications,¹² limited availability of disability-specific data,¹³ and inadequate crisis standards of care¹⁴ have exacerbated existing inequities.^{14,15} Additionally, lockdown requirements and social distancing regulations caused disruptions to accessing both routine health care services¹⁶ and community support networks.³ Many people with disabilities also have pre-existing conditions that place them at increased risk of COVID-19 infection and related mortality.¹⁷

Planning that fails to account for the needs of people with disabilities can lead to barriers in accessing critical services and resources during an emergency. Additionally, emergency responders may not be trained or equipped to provide necessary assistance to people with disabilities, which can lead to further harm or injury during an emergency.¹⁸ Historic marginalization and implicit social biases further contribute to the increased risk for people with disabilities during emergencies.¹⁹

In accordance with federal guidelines,^{20,21} it is critical that health agencies at all levels of government include people with disabilities in emergency planning efforts to address systemic inequities.²² The Federal Emergency Management Agency (FEMA)'s Whole Community Approach provides a conceptual framework for emergency management focused on engaging community partners and leveraging existing social infrastructure²³ that has been implemented at both state²⁴ and local²⁵ levels. Rooted in this approach, disability subject matter experts who have disabilities themselves can be embedded within public health agencies. These experts can serve as active participants in emergency planning and help ensure issues impacting people with disabilities are addressed in emergency planning, response, and recovery efforts.

Methods

Project background

As part of a multi-component project to address the needs of people with disabilities during the COVID-19 pandemic, the Association of State and Territorial Health Officials (ASTHO), and the National Association of County and City Health Officials (NACCHO) applied funding issued by the US Centers for Disease Control and Prevention (CDC) of the US Department of Health and Human Services to embed disability subject matter experts, or disability specialists, within health departments. Jurisdictions were selected based on geographic representation, demographic characteristics (eg, disability prevalence, number of people from racial and ethnic minority populations), and COVID-19 burden as of the fall of 2020. Jurisdictions hired and placed 28 specialists, including people with disabilities,* across 16 states, 2 territories, and 10 cities and counties between January 2021 and July 2022 (Figure 1). ASTHO offered two hiring options for jurisdictions: ASTHO could either provide funding to the health agency to employ and compensate one full-time specialist or ASTHO could hire one full-time specialist to be employed and compensated

* ASTHO and NACCHO provided sample job descriptions to participating jurisdictions indicating preferred qualifications including a master's degree in public health, public administration, health policy, social work, or related field with equivalent experience considered in lieu of degree, at least 4 years of experience working with persons with disabilities and access and functional needs, and experience in project management, strategic planning, partner relations, and public health emergency preparedness and response. People with disabilities were encouraged to apply.

through Wanderley, a health-focused hiring agency, and embedded within the health agency. NACCHO provided funding to the local jurisdictions, and they were responsible for the hiring process for each Specialist. Hired specialists joined the program with a wide range of experiences and backgrounds, including people with experience in public health, emergency preparedness, disability services, disability advocacy, occupational therapy, healthcare, law, and military service. Specialists underwent onboarding training covering responsibilities and specialized topics related to disability inclusion and emergency preparedness within the first month of their positions, including NACCHO's disability and health competency training.²⁶

Specialists were tasked with updating state, territorial, city, and county health department emergency plans (eg, Crisis and Emergency Risk Communication plans) to better serve the needs of people with disabilities. Specialists partnered with local Public Health Emergency Preparedness (PHEP) programs and emergency management systems, community-based organizations, local government, nonprofit agencies, and other relevant entities to coordinate emergency planning, mitigation, and recovery efforts. Specialists also engaged in response-related efforts on COVID-19 and other co-occurring natural disasters including hurricanes, wildfires, and floods.

Baseline assessments

Specialists worked with their assigned jurisdictions to conduct standardized baseline health department capacity and partnerships assessments (Supplemental Digital Content available at: <http://links.lww.com/JPHMP/B349>) to identify existing gaps related to disability inclusion and emergency preparedness within the first few months of their employment. ASTHO led the development of the assessments based on a prior capacity assessment,²⁷ PHEP capabilities,²⁸ and COVID-19-related challenges. Specialists worked with staff across their health agencies to answer questions spanning topics of multilevel leadership; managed resources; state, territorial, and local plans; surveillance; training; workforce capacity; communication; mitigation, recovery, resilience, and sustainability efforts; and networked partnerships.

Specialists created improvement plans in collaboration with health department employees based on the baseline assessments, beginning by charting all identified gaps (ie, answers of "no," "never," or "not at all" on the assessments) by topic (eg, multilevel leadership, managed resources). Specialists organized gaps using a prioritization matrix developed by the ASTHO team based on urgency, importance, and feasibility. Improvement plans prioritized gaps by developing specific, measurable, achievable, realistic, timely (SMART) goals, detailing improvement actions, activities, baseline measurements, support, and resource requirements, evaluation measures, and long-term sustainability. Specialists addressed identified gaps and translated into sustainability plans activities that could not be completed during the project.

Learning community

Specialists participated in an ASTHO and NACCHO-led monthly discussion-based virtual learning community meetings. Sessions, typically 1 hour in duration, provided specialists with training around disability inclusion and emergency preparedness and opportunities to

share information and strategies for assessment completion and addressing identified gaps. ASTHO and NACCHO jointly held sessions monthly from January through December 2021. ASTHO continued to host sessions for ASTHO specialists through July 2022 and NACCHO continued to host sessions for NACCHO specialists through March 2022. Sessions routinely featured speakers from national public health agencies, health departments, and other disability and public health organizations, such as the American Association on Health and Disability, the National Council on Independent Living, and the World Institute on Disability. Specialists were required to attend all learning community sessions except in circumstances of unavoidable conflicts.

Evaluation framework

CDC, ASTHO, and NACCHO developed an evaluation framework using a mixed methods approach, assessing how specialists improved emergency response planning, mitigation, and recovery efforts for people with disabilities within their jurisdictions. Quantitative measures included number of specialists completing NACCHO's disability and health competency training²⁶ and average number of gaps addressed that were identified from the baseline assessments. Qualitative measures included types of new strategies implemented, barriers, and learned promising practices for disability inclusion in emergency preparedness. ASTHO and NACCHO collected evaluation data from specialists through their baseline needs assessments, program improvement plans, sustainability plans, midpoint and final reports, virtual meetings (ie, monthly learning communities and close-out calls), and evaluation surveys, and shared aggregated, deidentified results with CDC. Specialists indicated whether they identified as a person with a disability through an optional, anonymous online survey at completion of the program.

Analysis

CDC reviewed deidentified data to understand changes made to improve emergency preparedness for people with disabilities. We calculated the total number of gaps identified within jurisdictions by counting all answers of "no" or "never" (but not "sometimes" or "unsure") on the baseline needs assessments (Supplemental Digital Content available at: <http://links.lww.com/JPHMP/B349>). Two coders (RAC and AW) reviewed aggregate summaries of evaluation results and presentations from virtual meetings and used a deductive approach to categorize content based on whether it was a strategy to address an identified gap, a barrier to implementing the improvement plan, or a promising practice for sustainability. Next, we assigned codes representing each barrier to implementation of the improvement plans using an inductive approach, and discussed all discrepancies until agreement was reached. We grouped common codes into broader themes representing each barrier and categorized promising practices for sustainability. NACCHO and ASTHO reviewed the analysis to verify the categorization of strategies, barriers, and promising practices, ensure themes captured original meaning of the specialists, and confirm sustainability activities and promising practices were relevant for addressing each barrier.

This work was deemed a nonresearch program evaluation according to the CDC's interpretation of federal regulations defining research (<https://www.cdc.gov/os/integrity/>)

[docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf](#)) and exempt from CDC IRB approval.

Results

Total number of specialists with a disability was unknown. About one-third of NACCHO and ASTHO specialists completing an anonymous survey self-identified as a person with a disability (n = 7 of 23). Additionally, during check-ins or learning community meetings, 10 ASTHO specialists self-identified as a person with a disability.[†] It is unknown why specialists chose to self-identify in check-ins and meetings, but not the survey.

Identified gaps and implemented strategies

Overall, specialists identified 1,010 gaps within the 28 jurisdictions (approximately 36 gaps per jurisdiction) across 8 needs assessment categories, summarized in Table 1. We list the assessment questions included under each assessment category in Supplemental Digital Content available at: <http://links.lww.com/JPHMP/B349>. After completing the assessments, specialists reported gaining essential insight into the existing capacity for disability inclusion in emergency preparedness within their jurisdictions. The largest total number of identified gaps was related to mitigation, recovery, resilience, and sustainability efforts (n = 213), while the largest proportion of gaps (63.8% of total possible) was related to state, territorial, and local plans. Other assessment areas with a sizable proportion of identified gaps included multi-level leadership (51.4%) related to a lack of commitment from agency leaders; managed resources (51.2%), including insufficient funding to address the needs of people with disabilities; and training (45.4%).

On average, specialists focused on addressing three of eight categories of gaps identified in the baseline assessments. Many collaborated with disability partner organizations to review plans, and all offered revisions to the jurisdiction's emergency plans. Another common area of focus was mitigation, recovery, resilience, and sustainability efforts to address the ongoing COVID-19 pandemic. Strategies to address gaps under this category included working to ensure equitable access to COVID-19 vaccination within their jurisdictions, such as collaborating with local organizations and medical personnel to administer COVID-19 vaccines for people with disabilities, and coordinating transportation to vaccine clinics.

Barriers and promising practices related to disability inclusion

We identified eight themes summarizing barriers that specialists mentioned in their roles at the individual (ie, staff), organizational (ie, health department), and community (ie, people with disabilities served by the jurisdictions and local disability-led or disability-serving organizations) levels (Table 2).

Individual-level barriers—Limited health agency staff capacity was a commonly mentioned barrier, including insufficient staff time and resources and frequent leadership transitions. One specialist commented that “*emergency preparations for persons with*

[†]NACCHO did not evaluate specialists' lived experience with disability outside of the anonymous survey.

disabilities are minimal and that is not because the agency does not care; it directly correlates to the lack of manpower and resources.” To address limited staff capacity, specialists suggested ensuring that health department staff are aware of existing resources. One training mentioned as being particularly helpful was the Association of University Centers on Disability (AUCD)’s Prepared4All: Whole Community Inclusive Emergency Planning.²⁹

Specialists mentioned limited disability subject matter expertise among health agency staff was a barrier to changing policies and procedures, as staff may not understand the importance of including people with disabilities across preparedness, response, and recovery activities. One specialist summarized, “*capacity and commitment [to people with disabilities and to satisfy the goals of the project] is not seen across the full health agency... work continues to be siloed and further advocacy is needed to ensure individuals with disabilities and others with access and functional needs are considered with all decisions.*” Specialists suggested health agencies implement training requirements related to disability inclusion and emergency preparedness for staff and monitor compliance to ensure accountability. Several specialists also mentioned their own limited subject matter expertise hindered their ability to communicate the importance of their work effectively to health department employees. Although some specialists were experts in disability inclusion or had disabilities themselves, many did not have formal training or experience in the intersection of disability and emergency preparedness. Specialists stated that peer-to-peer sharing between specialists and technical support from ASTHO and NACCHO were essential tools for building the knowledge and skills necessary for accomplishing their objectives.

Organizational-level barriers—Specialists described challenges at the organizational level, including limited availability of data inclusive of people with disabilities to inform decision making. One specialist explained that data are not shared between departments, are updated infrequently, and do not allow for disaggregation by disability status or type due to limitations in data collection. Many specialists also found there was no precedent for analyzing available disability data, due to limited personnel data access or analytic capacity, even when data sharing agreements between disability-serving organizations and the health department exist. One specialist suggested establishing a permanent office of analytics to regularly analyze existing sources of data for programmatic use. Specialists found success in forming a disability data workgroup to discuss ongoing data-related issues and share best practices for improving disability data collection and access within their jurisdictions.

Several specialists noted a lack of organizational readiness to move towards accessibility and inclusion limited their ability to gain buy-in and accountability. Some specialists found navigating division and inter-departmental structures complex. Several specialists cited explaining legal requirements under the Americans with Disability Act (ADA) and personal traits including persistence and consistency to gain the trust of agency leadership as key factors that helped them succeed.

Another common difficulty reported was challenges coordinating across and within government agencies, such as the disconnect between health department and emergency management or disability services (ie, Medicaid). One idea offered was to create a central

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coordinating office for disability work at the health agency. Another specialist suggested that agency leadership hold yearly check-ins to discuss the current legislative landscape including state and federally directed changes in public health and emergency management pertaining to people with disabilities.

Finally, specialists mentioned limited administrative readiness for change, including challenges with the specialist hiring process, the time-limited nature of the project (ie, 18 months), and requirement to work remotely due to COVID-19 restrictions limited their impact on health agency policies and protocols. One supervisor stated, *“we really need a culture shift with our department and that comes with time. While our Specialist did their best to create relationships within our department, this type of work may have been better over a 3–5 year project period.”* One specialist reflected that *“having a seat at the table makes a difference, however, without continued funding the gains made will be lost.”* Challenges related to the short duration were often experienced by participants at the state and territorial level, where many specialists could only provide suggestions on how jurisdictions could update emergency plans due to state policy regarding scheduled frequency for updating plans.

Community-level barriers—At the community level, specialists mentioned government mistrust following historic marginalization and mistreatment of the disability community. To address community hesitancy to work with the government, one specialist suggested the health department *“focus on maintaining relationships within the disability community and encourage new volunteers...highlight the impact and importance of input from people with disabilities in emergency preparedness and the outcome if they are not included.”* Persistent outreach, including dissemination of disability data and information to the disability community, use of social media to advertise for volunteers, and routine community checks, were helpful strategies for increasing buy-in from community organizations. Another specialist found that attending local disability partners’ community events helped build trust.

Another community-level barrier was few pre-existing partnerships with the disability community. Several specialists found engaging with community partners on a recurring basis was effective for deriving partnerships between public health agencies and community-level private organizations. One specialist hosted weekly discussion sessions with their state’s Governor’s Council on Developmental Disabilities to plan for an equitable distribution of the COVID vaccine and develop a plain language guide for people with disabilities.

Overall program evaluation

According to feedback from specialists and their supervisors, health agencies learned where they could strengthen disability inclusion efforts and targeted activities. Participants noted the program’s flexibility allowed jurisdictions to incorporate the lessons learned into broader health equity efforts tailored to their needs. Supervisors stated that specialists brought a unique skill set and lived experience providing new perspectives and credibility. One supervisor reflected that *“with the specialist in place, our organization has increased its capacity to engage more partners, reach more isolated communities, and bridge gaps more*

effectively. *Enhancing and expanding existing workgroups and mitigating communication barriers are the greatest successes to date.*” Supervisors indicated that having someone dedicated to disability inclusion provided critical support during an unprecedented time and their jurisdictions would benefit from continuation of the specialist position. One supervisor explained that “*frequently, we get grants where we need to find extra hours in the day to complete deliverables and it isn’t always the most helpful for increasing buy-in...being able to say this project needs to be a full-time job by hiring a temporary specialist was helpful.*” Specialists noted that responsive community partners and advocates, receptiveness of their emergency preparedness and management teams, and leadership buy-in all supported their ability to succeed.

Specialists reported they benefitted from peer learning through learning communities, where they were able to develop skills tailored to their work, share strategies for success, and find opportunities to connect across jurisdictions. Information and resources shared within the sessions led to action outside of the community of practice, such as building trust and relationships with partners, setting up vaccination clinics, implementing improvement plans, and sharing resources related to disability inclusion and emergency preparedness within their health departments. ASTHO and NACCHO worked closely with disability partners such as the World Institute on Disability to provide training in health equity, emergency planning, power outage preparedness, and legal requirements under the ADA. Specialists shared skills and resources with jurisdiction staff, broadening the impact beyond the learning community. Specialists stated that the learning community format allowed them to collaborate across various levels of government and accelerated successful strategies across jurisdictional lines.

Discussion

ASTHO and NACCHO disability specialists serving within state, territorial, and local health departments improved jurisdictional ability to meet evolving public health needs for the entire community during emergencies, particularly people with disabilities. However, barriers identified by specialists in the jurisdictional needs assessments showed that there is much room for improvement. Concerted effort towards disability inclusion is necessary at all levels of government and community-level response to public health emergencies.²²

Specialists identified challenges related to the availability of disability-related data to inform decision making during the COVID-19 pandemic, mirroring concerns that have been described elsewhere.^{10,13,30} Leaders from urban city and county health departments have previously expressed challenges with receiving accurate and timely data as many rely on state health department data sources such as vital statistics, resulting in multi-year delays in receiving updated data.³¹ Similarly, specialists noted time lags in receiving updated data as a barrier to implementing disability-inclusive programs and services in their jurisdictions. The paucity in disability data can lead to life-threatening oversights and the perpetuation of social injustices for people with disabilities during public health emergencies, including the response to COVID-19.³⁰

Specialists also identified limited staff capacity and organizational readiness to move towards accessibility and inclusion as two major persistent barriers. State and local governments have a legal obligation to provide accessible programs and services under the ADA.³² Given limited resources available to many health departments,³³ this program offers a key training opportunity for public health professionals while enhancing jurisdiction's ability to ensure accessibility and include people with disabilities into essential public health preparedness and response efforts. Inclusion of people with disabilities in public health careers is essential for addressing existing inequities.³⁴ However, only one-third of disability specialists who responded to an anonymous question regarding their disability status reported having a disability themselves, possibly indicating jurisdictional challenges reaching potential applicants. Future recruitment efforts for similar programs could increase the number of people with disabilities hired by actively recruiting through disability-led organizations. Replication of the current program could help address competing priorities and inadequate support for positions that focus on disability subject matter expertise within health agencies to improve understanding of legal requirements under the ADA and better address disability inclusion.

Specialists from all jurisdictions faced challenges related to addressing vaccine hesitancy. Specialists focused on building partnerships and community buy-in with local organizations, strategies which hold promise in addressing vaccine hesitancy among people with disabilities³⁵ and other marginalized groups.³⁶⁻³⁸ One specialist developed monthly community forums in collaboration with disability partners who were able to share resources around accessible vaccine access points. Provision of home-based vaccines can help eliminate significant challenges for people living with disabilities, including transportation barriers for those with mobility issues, and, for those who have experienced medical trauma or have sensory issues, being vaccinated in a familiar setting can reduce tension and ease fears.³⁹

A virtual learning community among disability specialists was successful for exchanging knowledge and best practices related to disability inclusion and emergency preparedness. Specialists used information from learning communities to impact their health agencies through activities such as improving practice, training, updating policies, and creating new partnerships. The learning community was central to capacity building and provided specialists with the opportunity for discussion and collaborative problem solving for issues they faced. Lessons learned and information shared permeated beyond the cohort of specialists to the broader health agency. Health agencies can use this learning community as a model to increase staff capacity to include people with disabilities in emergency response.

Limitations

Our evaluation of the disability specialist program has limitations. First, baseline assessments were self-reported by staff within participating health departments which may have introduced bias. Second, due to the small number of participating jurisdictions and need to maintain confidentiality, we were unable to examine differences in gaps identified or barriers experienced by jurisdictional characteristics such as level (city, county, state, or territory) or demographic breakdown. However, the program had wide geographic

representation across the United States. Third, results from our evaluation may not be representative of the participating jurisdictions depending on the specialists' placement within the organization (eg, some worked more closely with agency leaders than others). Fourth, few specialists self-identified as a person with a disability, potentially impacting the success of the program. Finally, we were unable to assess longer-term outcomes and sustainability of new policies and programs implemented within participating jurisdictions. Future studies could evaluate the long-term impact of embedding disability specialists within local, state, and territorial health departments.

Conclusion

Recovery from the COVID-19 pandemic offers an unprecedented opportunity for communities to rebuild with a focus on equity.³⁰ The disability specialist program reinforced the value of collaboration, providing a direct conduit between the disability community and health agencies to identify, elevate, and address barriers. This program also highlighted the importance of inclusive public health preparedness, accessible communications, and collaboration between emergency management and public health. Finally, this program identified a larger workforce need for people with disabilities to serve as public health professionals in all programs, not just equity and disability offices. Their expertise and lived experiences are valuable to all parts of public health.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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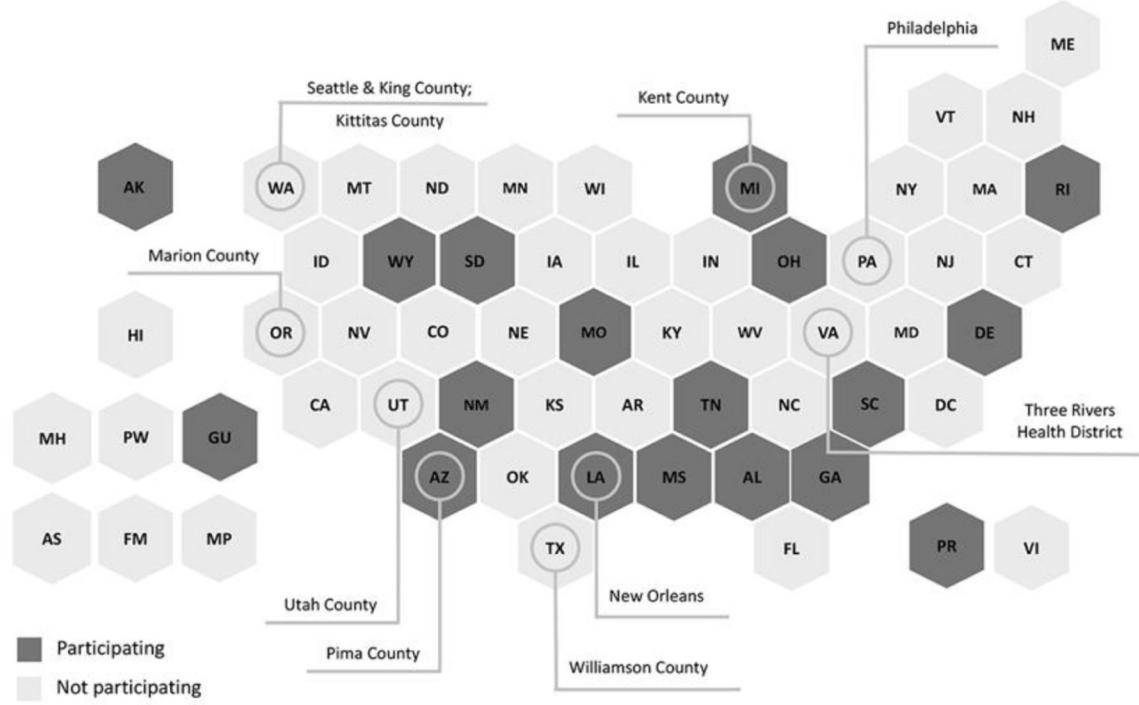
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Implications for policy & practice

- Integrating people with disabilities within public health departments can improve state, territorial, and local emergency planning.
- Health departments may use lessons learned from disability specialists, such as how to build and strengthen partnerships with the disability community, to improve health department capacity to respond to public health emergencies and inform future equitable response efforts at the state, territorial, and local level.
- Embedding disability specialists within health departments offers jurisdictions an opportunity to promote and integrate disability inclusion across all phases of the disaster cycle – mitigation, preparedness, response, and recovery – each phase critical to ensuring equity for the disability community before, during, and after disasters.
- Health agencies can use the learning community model as a method for sharing best practices and resources through peer networks to increase staff capacity to include people living with disabilities in emergency response.
- Hiring people with disabilities within health departments can strengthen the public health workforce to address the needs of people with disabilities.
- The same inequities contributing to health disparities for people with disabilities also place people with disabilities at disproportionate risk during disasters; therefore, integration of disability inclusion across all public health programs and activities will benefit the whole community.

**FIGURE 1.**

Placement of State, Territorial, City, and County Disability Specialists – United States, January 2021 to July 2022 Figure 1 displays the location of disability specialists, including 16 states, 2 territories, and 10 local jurisdictions between January 2021 and July 2022. Figure reproduced from: <https://www.cdc.gov/ncbddd/humandev/covid-19/inclusion-of-people-with-disabilities-preparedness-planning-response.html>.

TABLE 1
Gaps Identified on 28 Specialist Jurisdictional Needs Assessments and Strategies Disability Specialists Implemented to Address Gaps

| Needs Assessment Category | Example of Gap | Gaps Identified ^a Across 28 Jurisdictions | | | Strategies Implemented to Address Gap |
|-------------------------------------|--|--|----------------|---------|--|
| | | Number | Total Possible | Percent | |
| Multi-level leadership ^b | <ul style="list-style-type: none"> Public health leaders in the health agency have not expressly committed to addressing issues affecting people with disabilities | 38 | 74 | 51.4% | <ul style="list-style-type: none"> Gave regular presentations to heads of jurisdictions on the importance of including people with disabilities across all health department activities |
| Managed resources ^b | <ul style="list-style-type: none"> Insufficient funding to address the needs of people with disabilities | 43 | 84 | 51.2% | <ul style="list-style-type: none"> Assisted health department staff with writing proposals for grants around health equity to continue and expand existing essential health equity activities |
| State, territorial, and local plans | <ul style="list-style-type: none"> People with disabilities are not included in updating emergency plans Emergency operations plans do not include information about the needs of people with disabilities | 125 | 196 | 63.8% | <ul style="list-style-type: none"> Collaborated with disability partner organizations to review state/territorial/city/county emergency operation plans on an annual basis Increased agency awareness of the importance of including people with disabilities in emergency planning Wrote the jurisdiction's first access and functional needs (AFN) annex Collaborated with emergency planners who were already involved with the COVID-19 response to help ensure people with disabilities were included in emergency planning Collaborated with other disability specialists to review community outreach plans Involved people with disabilities in health department after action reporting and improvement planning following public health responses |
| Surveillance | <ul style="list-style-type: none"> Preparedness department does not analyze or use disability data Program does not collect data related to people with disabilities | 137 | 354 | 38.7% | <ul style="list-style-type: none"> Helped to develop county profiles across states to include qualitative and quantitative data from the surveys, listening sessions, and data sources including annual surveys, Medicaid, and other jurisdictional-level data Established a Disability Data Workgroup for specialists to share challenges and promising practices within their jurisdictions Informed agencies of the availability of existing disability data Identified current data sharing agreements in place and helped to add new collaborations where needed Recommended the health department require ongoing analyses and structured reporting of available population-level disability data to inform emergency preparedness and response needs |
| Training | <ul style="list-style-type: none"> Lack of general trainings to preparedness staff on the needs of people with disabilities Training on the needs of people with AFN for public health staff, emergency managers, and first responders does not currently exist within the health department | 139 | 306 | 45.4% | <ul style="list-style-type: none"> Shared existing disability and health trainings with health department staff, including NACCHO's Health and Disability training Developed a training for Community Health Workers (CHWs) that incorporated new content and leveraged existing materials Conducted a needs assessment with emergency preparedness staff to determine disability training needs Completed Cultural Competency and Clinic Equity trainings Worked with health department leadership to identify the ideal percentage of staff that will be trained on disability and AFN during a disaster Held Functional Assessment Service Team (FAST) training for staff Created a training plan that includes disability awareness and etiquette training for health department staff and volunteers Created a first responder training highlighting challenges and needs for people with AFN during a disaster |

| Gaps Identified ^a Across 28 Jurisdictions | | | | | |
|--|---|--------|----------------|---------|---|
| Needs Assessment Category | Example of Gap | Number | Total Possible | Percent | Strategies Implemented to Address Gap |
| Workforce capacity ^b | <ul style="list-style-type: none"> Needs of people with disabilities are not included in planning and conducting emergency preparedness exercises | 61 | 212 | 28.8% | <ul style="list-style-type: none"> Incorporated people with disabilities in the emergency planning processes and invited them to participate in tabletop exercises Participated in local university's tabletop exercises for emergency preparedness |
| Communication | <ul style="list-style-type: none"> Inaccessible communications | 193 | 474 | 40.7% | <ul style="list-style-type: none"> Integrated accessible communication resources within existing preparedness plans Hosted several virtual events to reach the local community, including a Facebook live panel with a state health official and a self-advocate with Down Syndrome, and a vaccine public service announcement (PSA) with the state governor Helped to update the Department of Health website, including adding information about the ADA, 508 accessibility standards, Federal Emergency Management Agency (FEMA) trainings, and a list of potential disability organizations and partners Worked to alter department policies to make communications ADA compliant Reviewed the health department website for accessibility and provided recommendations for improvement to the communications department Offered trainings to health department personnel on the procedures and protocols for communication dissemination during an emergency. Advocated to leadership for stronger collaboration with disability organizations, using examples of collaborations in other jurisdictions. |
| Mitigation, recovery, resilience, and sustainability efforts | <ul style="list-style-type: none"> Jurisdiction does not have plans to provide accessible transportation to receive COVID-19 vaccinations and testing for people with disabilities Jurisdiction does not always ensure sites of gathering, such as shelters or vaccination sites, are accessible for people with disabilities | 213 | 718 | 29.6% | <p><i>COVID-19 vaccination</i></p> <ul style="list-style-type: none"> Worked with local community organizations, government organizations, and medical personnel to increase access to COVID-19 vaccines for people with disabilities and people who are homebound (eg, partnered with County EMS Paramedics and Meals on Wheels to coordinate vaccines for people who are homebound, long term care facilities, assisted living centers, intermediate care facilities, and outpatient treatment clinics; helped arrange transportation to vaccine clinics; helped establish a jail vaccination program; developed a partnership with a disability advocacy organization to help deploy mobile vaccination vans across the state) Increased accessibility of vaccination sites (eg, increased access to interpreters at vaccination sites; partnered with the National Guard to assess vaccination site accessibility; helped develop trainings for National Guard staffing vaccination sites) Created and distributed a vaccination toolkit about vaccinating people with disabilities Led a team of public health partners in weekly discussions regarding equitable distribution of COVID vaccines <p><i>Preventing involuntary institutionalization</i></p> <ul style="list-style-type: none"> Reviewed and assessed hospital protocols for discharging people with disabilities after emergencies—including ongoing emergencies such as COVID-19 or acute emergencies (eg, natural disasters or other events) <p><i>Sheltering</i></p> <ul style="list-style-type: none"> Assigned Emergency Support Function (ESF) #6 – Mass Care, Emergency Assistance, Housing, and Human Services and ESF #8 Public Health and Medical Health and Medical Services departments, emergency coalition partners, disability organizations, and those qualified in ADA compliance to identify locations that are suitable for sheltering and are located within proximity for emergency paratransit units <p><i>Emergency communications</i></p> <ul style="list-style-type: none"> In partnership with the Governor's Council on Developmental Disabilities, helped to develop a plain language guide for people with disabilities to understand the pandemic Hosted listening sessions across the jurisdiction on the importance of addressing access and functional needs |
| Networked partnerships ^c | Health agency does not receive input directly from people | 61 | 166 | 36.7% | |

| Gaps Identified ^a Across 28 Jurisdictions | | | | | | |
|--|--|--------|----------------|---------|--|--|
| Needs Assessment Category | Example of Gap | Number | Total Possible | Percent | Strategies Implemented to Address Gap | |
| | with disabilities on emergency preparedness planning | | | | <ul style="list-style-type: none"> Presented on specialist activities at disability partner organizations Provided opportunities for partners to provide feedback and integrate their suggestions within a health department strategic plan Developed an access and functional needs advisory committee comprised of community partners such as the local University Center for Excellence in Developmental Disabilities (UCEDD) Established a yearly plan for follow-up with community partners | |

^aNumber of gaps identified were calculated by counting all answers of “no,” “never,” or “not at all” (but not “sometimes” or “unsure”) on the baseline needs assessments. See Supplemental Digital Content available at: <http://links.lww.com/JPHMP/B349> for a summary of all questions counting towards the total possible number of gaps.

^bIncluded on health agency assessment only.

^cIncluded on partnership assessment only.

TABLE 2
Barriers to Implementation of Specialist Improvement Plans and Promising Practices to Overcome Barriers and Help Ensure Sustainability

| System Level | Barriers To Implementation of Improvement Plan | Example of Barrier | Promising Practices to Overcome Barriers and Help Ensure Sustainability |
|------------------------|--|---|--|
| Individual | Lack of disability subject matter expertise | <ul style="list-style-type: none"> Limited understanding of the importance of disability inclusion and emergency preparedness among health agency staff Low perceived need for additional disability inclusion training among health agency staff Specialist did not have formal training or experience in the intersection of disability and emergency preparedness Specialist had difficulty communicating the project purpose and its impact with health department employees Perceived lack of available standardized training on disability inclusion and emergency preparedness | <ul style="list-style-type: none"> Embed a disability specialist within the Diversity, Equity, and Inclusion office Implement an agency mandate for training related to disability inclusion and emergency preparedness for all emergency preparedness staff and track current staff training in a database to ensure accountability Use the Continuity of Operations Plan (COOP) to require disability integration training for emergency response leaders Make health department staff aware of existing resources, such as AUCD's Prepared4All training |
| Limited Staff Capacity | | <ul style="list-style-type: none"> Limited time and resources available Limited staff and high staff turnover Difficulty integrating project activities with existing staff responsibilities Difficulty achieving buy-in from overburdened public health workers Health department prioritized responding to the COVID-19 pandemic over other public health issues | <ul style="list-style-type: none"> Employ people with disabilities to help with staff turnover and gain disability perspective Clarify with staff that updating emergency plans will not be strenuous to keep up with; things will not need to be changed regularly Extend the specialist position beyond one year as a full-time position within the health department |
| Organizational | Difficulty defining, measuring, or using disability data | <ul style="list-style-type: none"> Lack of a common definition for disability; for example, funding streams often determine which definitions are used at health agency level, which may be different from partners Lack of precedent for analyzing disability data as existing data points have never been pulled or examined by the jurisdiction Data are not currently examined or updated on a regular basis Data systems are fragmented limiting data collection and sharing Lack of inclusion of disability within existing data systems (limiting the ability to disaggregate outcomes by disability status and type) | <ul style="list-style-type: none"> Compile existing sources of data (eg, qualitative and quantitative data from the surveys, listening sessions, and BRFSS data, Medicaid data, and state-level data) to show a broader picture of the potential/observed impact of disasters on people with disabilities Establish a permanent Office of Analytics to regularly pull existing sources of data; build a digital platform to input and analyze data; and incorporate data into narratives for programmatic use Ensure data can be easily accessed and used by agency staff (eg, including disability data on the agency's dashboard) Inform agencies of the availability of the data for use via press release, social media, etc. Create a list of organizations serving people with disabilities that currently submit data to the health department and research organizations that do not; work with organizations to create new agreements Participate in a disability data workgroup with other state, territorial, and local leaders to share best practices for improving disability data collection and access |
| | Lack of organizational readiness to move towards accessibility and inclusion | <ul style="list-style-type: none"> Difficulty achieving buy-in from leadership/challenges scheduling meetings with health agency leadership Difficulty in accessing leadership outside of preparedness offices Difficulty navigating complex division and interdepartmental structures to remedy accessibility issues Difficulty aligning efforts with other health disparities programming Limited foundational work and general knowledge of legal requirements under the Americans with Disabilities Act (ADA) and disability equity | <ul style="list-style-type: none"> Maintain consistency and persistence in efforts to gain the trust of agency leadership and partners Discuss the legal and moral responsibilities for including people with disabilities in preparedness planning with agency leadership Hold conversations on the importance of including people with disabilities within the health department on an ongoing basis |

Promising Practices to Overcome Barriers and Help Ensure Sustainability

System Level Barriers To Implementation of Improvement Plan

| System Level | Barriers To Implementation of Improvement Plan | Example of Barrier | Promising Practices to Overcome Barriers and Help Ensure Sustainability |
|---|--|---|---|
| Challenges coordinating across and within government agencies | <ul style="list-style-type: none"> • Difficulty updating plans that were already underway • Shifting priorities • Challenges establishing new structures without precedent for sharing information related to disability and AFN • Public health and emergency management are siloed and do not communicate with one another • Public health and disability service (Medicaid) are disconnected | <ul style="list-style-type: none"> • Establish a central coordinating office at the health agency for disability work focusing on changes in state or federal legislation related to the public health and emergency management industries • Hold a yearly public health emergency preparedness (PHEP) check-in with leadership | |
| Limited administrative readiness for change | <ul style="list-style-type: none"> • Challenges with the specialist hiring process, including difficulty with procurement and HR systems • Time limited nature of the project and lack of ongoing funding for the specialist position • COVID-19 prohibited in-person meetings and group activities | <ul style="list-style-type: none"> • Embed specialists in their positions for longer than 1 year • Roll over specialist activities to a trained project designee to ensure the sustainability of project activities | |
| Community | <ul style="list-style-type: none"> • Disability community hesitation to work with government entities due to mistrust • Vaccine hesitancy | <ul style="list-style-type: none"> • Focus on building partnerships and community buy-in with local disability organizations • Co-develop a Disability Equity Action Plan with disability community leaders • Focus on disseminating data and information to support the need for involvement in emergency preparedness among disability organizations and utilize their social media to continuously advertise for volunteers in their communities • Hold routine (suggested as often as weekly but at least quarterly) community check-ins and incorporate feedback into emergency plans • Solicit feedback through regular surveys and after-action reports to obtain suggestions for improvement • Attend local disability partner's community events | |
| Lack of pre-existing partnerships | <ul style="list-style-type: none"> • Challenges with coordinating partnerships • Difficulty identifying agencies to incorporate involvement of disability community in planning or exercises | <ul style="list-style-type: none"> • Engage with community partners to derive public-private public health partnerships • Conduct outreach to people with disabilities to establish transportation to vaccine clinics and communication during emergencies • Obtain buy-in from nursing staff at clinics • Develop partnerships between community paramedics and disability organizations • Include individuals with disabilities in the planning process and invite them to participate in table-top exercises | |