Disability-Inclusive Emergency Preparedness and Community Perspectives

RESEARCH AND OUTCOMES IN ALAMEDA COUNTY

By The Center of Independent Living and
The World Institute on Disability

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Introduction, Purpose, and Background

The experiences, challenges, and needs of people with disabilities during times of disaster and emergency must be prioritized by emergency management, elected officials, and our communities that care for one another. Disabled people have significant wisdom and resilience to share when it comes to preparing for, surviving, and recovering from disasters and emergencies in ways that are accessible and creative, and that ultimately increase the resiliency of our communities at large.

The following report summarizes and highlights collaborative work completed by the World Institute on Disability (WID) and the Center for Independent Living (CIL). This work was intended to gather insight and information from cross-disability communities related to their perspectives, experiences, and expectations of the County of Alameda and others. Listening sessions, surveys, and focus groups were used as data collection methods and the results were used to create summary observations and recommendations.

CIL and WID are disability-led organizations located in Alameda County who both engage in work supporting people with disabilities in living in their communities of choice, with access to equitable opportunities and services. Both organizations conduct projects and programs related to disability-inclusive and accessible emergency preparedness and disaster planning.

World Institute on Disability

The World Institute on Disability ("WID") was established in 1983 as one of the first global disability rights organizational think tanks, founded and continually led by people with disabilities. WID is a global leader in disability inclusion in emergency preparedness, disaster risk reduction, and climate resilience. WID provides consultation, technical assistance expertise and training for public and private entities to create sustainable systems, policy and practice change that improve outcomes for people with disabilities across the disaster life-cycle. WID elevates the lived experience and expertise of disabled people and disability-led organizations to advance universal accessibility and whole community inclusion in comprehensive emergency management. WID has partnered with CIL to identify and address the emergency preparedness and disaster planning needs that impact disabled people in Alameda County.

The Center for Independent Living

Center for Independent Living
Access for All

The Center for Independent Living ("CIL") emerged out of the Independent Living and Disability Rights movements of the 1970s, and was founded in 1972 as the first independent living center providing peer-led services and advocacy to support cross-disability communities in living independently and interdependently in their communities of choice. CIL provides a diversity of services, including assistive technology, personal attendant services, housing counseling and home modifications, travel training, vocational skill-building, youth empowerment and community organizing, benefits counseling and information & referral services, and much more.

CIL launched its Emergency Preparedness and Resiliency Program in 2022 to build emergency readiness, response, and recovery by people with disabilities, for people with disabilities; our services focus on areas often left out of traditional emergency management, like accessibility, assistive technology and mobility devices, disability hacks during disasters, and key community resources for disabled people and older adults. In the past two years, our program has launched several exciting initiatives, including Emergency Preparedness 101 and individual emergency planning workshops built for cross-disability communities and older adults; technical assistance and advocacy with local emergency managers; and a Peer Ambassador Program, where disabled people and older adults are paid to create their own community projects related to emergency preparedness and resiliency.

A cornerstone of our program has been our collaboration with WID to identify needs, gaps, opportunities and strengths related to emergency preparedness for people with disabilities in Alameda County. The following report is a fruit of this collaboration, based on a year of community listening sessions, a county-wide survey, and focus groups.

PURPOSE

This project, which began with community listening sessions, evolved into a county-wide survey, deepened through focus groups, and now is summarized in this report, has several important purposes:

1 Understand the current state of emergency preparedness and disaster resilience across Northern Alameda's diverse disability population.

2 Identify needs, challenges, gaps, opportunities and strengths towards creating recommendations for City, County, State and community partners and community networks.

3 Support and train community members and Emergency Preparedness Peer Ambassadors as experts and as valuable resources for emergency management teams.

4 Build and deepen trusting and reciprocal relationships across diverse communities of organizations by/for people with disabilities and between the CIL and WID, and identify recommendations for City, County, State and community partners.

This project receives generous support from Listos California, a grant program of the California Governor's Office of Emergency Services (OES). Listos California supports community-based organizations and Indigenous tribes throughout the state to ensure every Californian, regardless of age, ability, income or language, has access to culturally competent resources to prepare for and respond to disasters. *ID: Listos California blue, yellow, and white circular logo with a California bear at its center and with 'Listos California' written on the outside of the circle*

The Center for Independent Living is also a Disability Disaster Access and Resources through California Foundation of Independent Living Centers (CFILC), and provides inclusive and accessible emergency preparedness services for people with disabilities before, during, and after times of disaster. *ID: Disability Disaster Access and Resources blue, red, and orange logo featuring an outline of the state of California, a water droplet, and crowd of people with various disabilities.*

PEOPLE WITH DISABILITIES ARE

2-4 TIMES

MORE LIKELY TO BE HURT OR DIE IN A DISASTER.

BACKGROUND OF ISSUES

Data from previous disasters shows that people with disabilities are two to four times more likely to be hurt or die in a disaster than other community members.[1] We know that multiple factors contribute to the disproportionate outcomes including ableism, an emergency management system that does not include the needs of people with disabilities, lack of skills of providers and responders. We also know that these barriers exist at the intersections of, and are compounded by, racism, classism and economic disenfranchisement. Although most people do not perceive themselves to be ableist, the perception of people with disabilities as less valuable can be found throughout emergency management and other service provider industries.[2]

Discrimination and social inequities before disasters increase the exposure of people with disabilities to risks and hazards; these include, but are not limited to decreased ability to access essential resources, housing in areas at risk of natural disasters, communities with pollutants but without health resources or access to healthy living options, lack of accessible transportation, and economic barriers.[3] Disparities that exist before disasters create an increased risk for people with disabilities, so when an emergency occurs and agencies have not planned to meet the needs of people with disabilities, the outcomes are disastrous. Research has also shown that the need for inclusive planning and response efforts must involve people with disabilities from various backgrounds and perspectives.[4] Additionally, inclusive emergency management and disaster planning require a disability human rights approach to create plans and procedures that value the lives of people with disabilities.

1 ESCAP Disability Inclusive Disaster Risk Reduction, October 2015. www.unescap.org/sites/default/files/pre-ods/E_CDR(4)_INF4.pdf

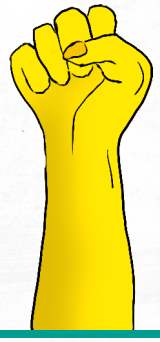
2 Journal of Health Affairs, vol 41, No. 10; Oct 2022; Lagu T, Haywood C, Reimold K, DeJong C, Sterling RW, Iezzoni L; Physicians' Attitudes about Caring for People With Disabilities. www.healthaffairs.org/doi/10.1377/hlthaff.2022.00475

3 Disasters DI Volume 40, Issue 3; November 2015, Stough L, Sharp A; Resch A; Decker C; Wilker N; Barriers to the long-term recovery of individuals with disabilities following a disaster. onlinelibrary.wiley.com/doi/abs/10.1111/disa.12161

4 Emerging Voiced in Natural Hazards Research; 2019; Craig L; Craig N; Calgaro E; Dominey-Howes D, Johnson K; Chapter 13 People with disabilities: Becoming agents of change in Disaster Risk Reduction; www.sciencedirect.com/science/article/pii/B9780128158210000205

PEOPLE WITH DISABILITIES IN EMERGENCY MANAGEMENT

There have been improvements in the emergency management system that are making it more possible for people with disabilities to be included in emergency planning and to shape the field with our vision and experiences. In 2010 FEMA launched the Office of Disability Integration and Coordination (ODIC) in support of the Disability Coordinator. This office gave FEMA the ability to send disability subject matter experts to disasters with other responders, providing essential disability information, they also provided expertise to the planning process and encouraged all emergency management offices around the country to include a disability coordinator in their staff. Centers for Independent Living (CILs) are partnering with local government agencies to help share emergency preparedness information, to provide their insights for plans, and to share their knowledge in disaster response. CalOES and many other State Emergency Management Offices have integrated Access and Functional Needs experts into their personnel. And disability organizations are collaborating with each other and with agencies to fill the gap and prevent people with disabilities from being left behind. This project is intended to build on what is happening in the country and the expertise of people with disabilities in Alameda County to improve the outcomes for Alameda County residents with disabilities in disasters. However, based on our research and input from the community, there is little evidence that County plans or local City plans include a necessary or adequate cross-disability input/leadership to create plans that include accessible structures, evacuations, transportation, temporary or long-term housing, points of distribution, communications, or disaster survivor programs.



ALAMEDA COUNTY

For example, in Alameda County's 2023 Draft Emergency Operations Plan (the most recent published by the county), Alameda County acknowledges that people with access, and functional needs may have additional needs before, during, and after a disaster, including "communication, medical care, maintaining independence, supervision, and transportation during evacuation and sheltering needs"; they specifically reference integration of interpreters and translators as important to "every stage of the process." However, later in its plan, Alameda County stops short of outlining the specific ways in

which they will operationalize access and safety for people with disabilities and people with access and functional needs during a disaster. Instead, they write that the County "will make every reasonable effort to see that culturally diverse community members and those with a disability will be able to access services or facilities provided by Alameda County during an emergency or disaster." They detail that "when available," shelters will be ADA compliant or compliant with modifications that are fully accessible to all occupants, and they explain that emergency communications that integrate interpreters, translators, and assistive technology will be provided "when possible." Alameda County's 2023 Draft Emergency Operations Plan discusses the need for additional resources and accommodations for people with access and functional needs and/or disabilities, but their plan has no commitments, concrete action items, or infrastructure to ensure this.

CITY OF BERKELEY

In another example, the City of Berkeley's 2024 Local Hazard Mitigation Plan[5] provides a comprehensive definition of people with access and functional needs that includes people with disabilities, and it acknowledges that many individuals are "disproportionately vulnerable during disasters." Throughout their Risk Assessment, they describe that people with access and functional needs might face additional challenges evacuating, that people with disabilities who are electricity-dependent are "especially vulnerable" during disasters that cause power outages, and that people with disabilities and older adults are most at-risk of heat-related illnesses during extreme heat events. However, people with access and functional needs and people with disabilities are nowhere mentioned in the "Mitigation Strategy" section of the City's plan; while the city can acknowledge the challenges and risks that people with disabilities might face before, during, and after a disaster, they are not able to respond with specific actions, plans, or resources to address those challenges and risks.

CITY OF OAKLAND

The City of Oakland's 2023 Emergency Operations Plan[6] provides more specific and actionable information related to people with disabilities and

5 "Local Hazard Mitigation Plan Update," City of Berkeley, updated June 2024, berkeleyca.gov/safety-health/disaster-preparedness/local-hazard-mitigation-plan-update

6 "2023 Emergency Operations Plan," City of Oakland, updated April 2023, www.oaklandca.gov/topics/2023-eop-update

people with access and functional needs before, during, and after disasters; for example, the City of Oakland has developed and adopted a Functional Needs Annex to their EOP that is intended to serve the needs of Oakland residents during a small scale, localized emergency or until the American Red Cross is able to take responsibility during more significant events, and they have a designated Functional Needs Coordinator as part of their Emergency Operations Center. The City of Oakland's EOP details that physical accessibility evaluations have been conducted at different sites surveyed as possible shelters, and that all site surveys are available in a database to facilitate site activation based on needs. Oakland's EOP also details many important communications and accessibility strategies for people with disabilities and AFN, including alternative formats for emergency communications (Braille, large print, translated materials, language interpreters, TTY, website accessibility and WCAG compliance). Upon review, the City of Oakland's EOP could have more specific considerations for ASL interpretation, captioning, and access fo Deaf/DeafBlind/Hard of Hearing communities. One strength within the City of Oakland might be that their ADA Coordinator is positioned to collaborate closely with the city's Emergency Management division.

While a more extensive review and analysis of local emergency operation plans/ hazard mitigation plans is outside the scope of this report, we believe that our findings above point to the importance of disability-led voice in emergency management spaces, and gaps and challenges that surface when disability leadership in disaster preparedness and resilience isn't present or prioritized. We hold that many improvements to city and county emergency plans and resources could be effectively and efficiently made with robust partnerships between emergency management teams and people with disabilities.

"We have witnessed the power of Nothing About Us, Without Us when it comes to emergency preparedness and resiliency for people with disabilities. If we don't see it in the world, we want—we need—to build it."

DRIVERS OF THIS PROJECT

A significant driver of this project has been our own experiences building an Emergency Preparedness program as people with disabilities, alongside people with disabilities; we have observed and experienced some of the same challenges and gaps when it comes to accessibility of emergency preparedness. We have felt the familiar anxiety and overwhelm, and we have felt the possibility and creativity of co-creating solutions amongst our community. We have witnessed the power of Nothing About Us, Without Us when it comes to emergency preparedness and resiliency for people with disabilities. If we don't see it in the world, we want–we need–to build it.

Despite advances in the field of emergency preparedness and resiliency for people with disabilities, there is still a long way to go. For example, one of the most frequent concerns that comes up for our consumers is the age-old, "in case of fire, use stairs" directive. For many disabled people, evacuating their building using stairs during a disaster is an inaccessible, non-possibility, and yet emergency managers by and large do not have alternative solutions for evacuating people with disabilities other than to wait for help from first responders–a solution which can feel terrifying, uncertain, and sometimes not like a solution, at all, especially as we know that help from first responders during a disaster cannot be guaranteed. We have supported consumers through concerns ranging from how they will evacuate with their medical equipment, to COVID-19 concerns at emergency shelters, to accessible safety positions during earthquakes, to accessing evacuation routes and maps for Blind and low vision people, and more.

2 Methods

People with disabilities participated in all roles and facets of the project, including project design and management, data collection administrators and participants, compiling outcomes, and developing reporting materials. The project used a mixed methods approach to the three phases of data collection beginning with a community listening session, followed by a county-wide survey, and three focus groups:

1. **COMMUNITY LISTENING SESSION** – Community members who had been engaged in CIL's Emergency Preparedness Program, and who were identified by CIL staff as having experience or knowledge in inclusive emergency management were invited to participate in a listening session to gather information about the types of concerns or questions that community members might have. The listening session information was used to assist in creating community surveys.
2. **SURVEYS** – CIL and WID distributed a community survey to Alameda County residents with disabilities who had experienced either a disaster or personal emergency event. The survey's overarching topic areas were personal preparedness, individual lived experience in a previous emergency or disaster, and perceptions and expectations of others in a future emergency or disaster.
    - Personal Preparedness questions identified perceptions of preparedness and what 'being prepared' means, the individuals' current status of preparedness, and their barriers and challenges to preparedness.
    - Lived Experiences questions identified if the person had experienced a personal emergency event that required response or a disaster that required community-wide response that included sheltering in place or evacuating their residence. For each situation, participants identified who assisted them and the effectiveness of the assistance, challenges related to receiving assistance, effective communication, accommodations, physical and mental health, and any positive or successful experiences.
    - Perceptions and Expectations questions identified individuals' expectations for future assistance, shelter services, and perceptions of roles and responsibilities of others.

3. **FOCUS GROUPS** – Survey respondents were provided the opportunity to volunteer to participate in focus groups to provide additional information. Approximately one-third of the participants expressed interest in participating in a focus group and multiple focus group sessions were held. Focus group sessions probed into what it means to 'be prepared' and reasons that people were not as prepared as they thought they should be, individuals' choices for assistance, what kinds of communication difficulties they experienced, how evacuation experiences could be improved, and what should be provided in a whole community inclusive shelter.

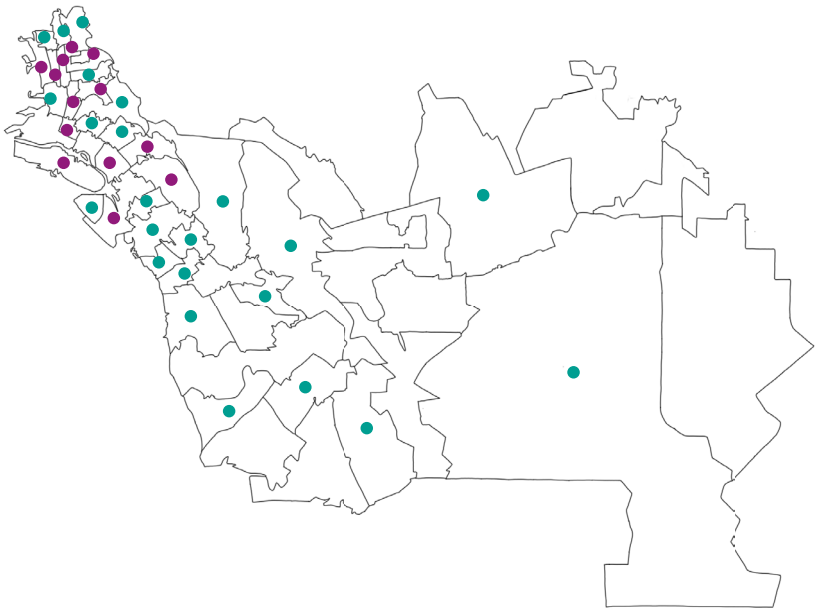
Information from each of these three methods built on each other to create a broad scope and a detailed inquiry into the disaster-related assets and challenges for individuals with disabilities in Alameda County.

3

Demographics and Analysis of Survey Responses

As part of the emergency preparedness experiences and expectations survey, CIL and WID collected demographic information specific to Alameda County. This helped to identify populations and demographic characteristics for other traditionally marginalized communities in addition to people with disabilities.

Out of 187 total responses, we received 125 complete responses, or 66.8% completeness. Responses were distributed fairly evenly across the zip codes in CIL's catchment area (Northern Alameda County), which includes the cities of Oakland, Berkeley, Albany, Emeryville, Piedmont, Alameda. We received the fewest survey responses within the City of Albany, which signals to CIL's Emergency Preparedness Program–and CIL as an organization–that Albany is a city where we would like to grow our presence, services, and community connections. While our survey was a county-wide survey, the responses were skewed towards residents of Northern Alameda County (79.9%), as this is where CIL has its offices, networks, and relationships. 68.1% of our respondents identified as living in an urban area, 29% in suburban areas, and 2.9% in rural areas.



ALAMEDA COUNTY

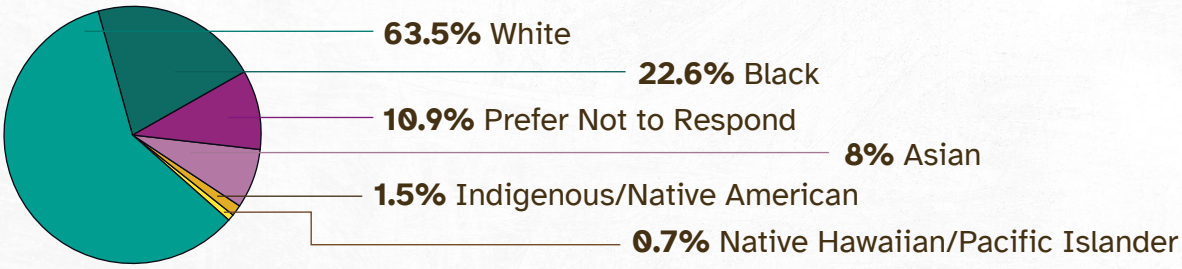
Each purple dot represents a zipcode receiving **>3%** of responses.

Combined, they represent 65.7% of all responses.

Each teal dot represents a zipcode receiving **<3%** of responses.

Combined, they represent 27.4% of all responses.

As part of our survey, we had an optional subset of questions regarding demographics of survey respondents. We learned that, out of the 136 demographic responses we received, survey respondents identified as:

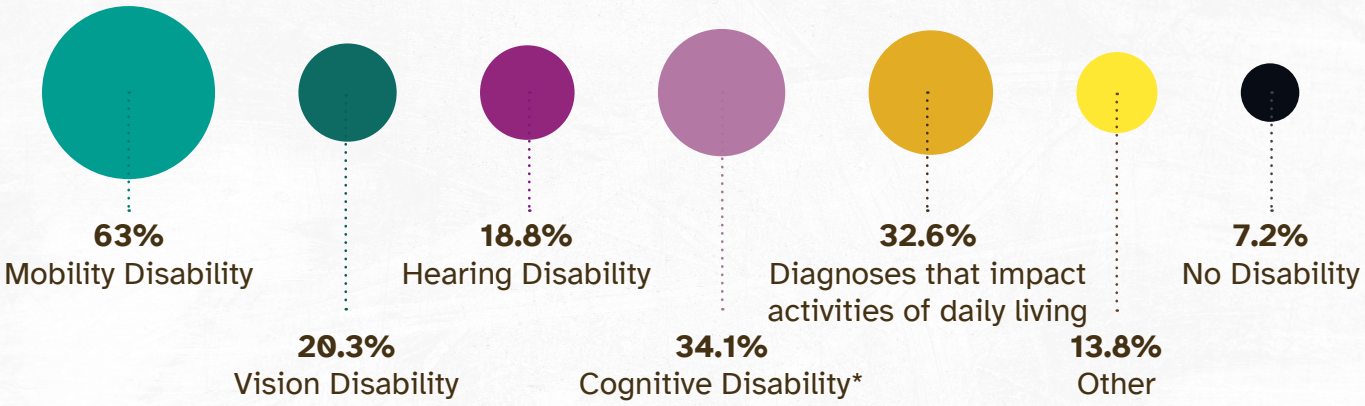


Multiracial participants could select multiple categories.

Further, in regards to ethnicity, 12.5% identified as Hispanic/Latino; 6.6% preferred not to respond, and 80.9% identified as not Hispanic/Latino.

When comparing our demographic results to the U.S. Census Bureau demographics for Alameda County, we found that we had a higher proportion of Black/African American respondents (10.7% in county to our 22.6%), and a higher proportion of white respondents (47% in county vs. our 63.5%). We had lower proportion of Latinx and Asian communities take the survey than are actually representative of our communities; one possible reason is that our survey was written in and publicized in English, which is an enormous gap and challenge in a county where 45.9% of the county lives in a home where a language other than English is spoken. This signals to CIL's Emergency Preparedness Program that we need to cultivate meaningful connections/relationships to communities whose primary language is not English.

Disability Demographics (participants chose all that applied):



**Includes learning disabilities, autism, intellectual and developmental disabilities, dementia, traumatic brain injury, mental health conditions.*

4

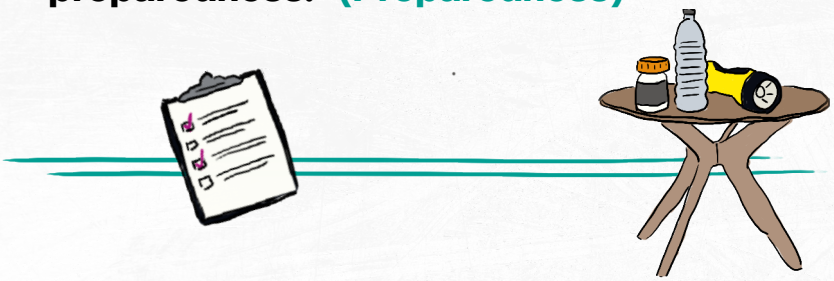
Key Take-Aways

Outcomes from the listening session, surveys, and focus groups were compiled and reviewed by both CIL and WID staff. Notable outcomes were categorized into four primary categories:

1. There is not a common understanding of what preparedness means and what is required to reach and maintain a state of 'preparedness'.
2. Most people who experienced an emergency or disaster were helped by family and friends and expect to receive help from family and friends in other emergency situations.
3. The three most significant difficulties for people were (1) taking necessary resources with them, (2) communicating with others, and (3) getting the assistance they needed.
4. The majority of negative impacts for people with disabilities that were reported were related to mental and emotional health.

The following sections of the report will delve into these key take-aways further, incorporating survey data and quotes and experiences from focus group participants.

1 There is not a common understanding of what preparedness means and what is required to reach and maintain a state of 'preparedness.' (Preparedness)



SUMMARY: There were a variety of responses to identifying what was required to 'be prepared'. The focus of individual preparedness was primarily on creating a kit, with much less focus on the components of an action plan, communications plan, evacuation plan or other related components to individual preparedness.

As a result, most people did not perceive themselves as completely prepared, citing limitations, restrictions or barriers to acquiring the supplies for their kits as reasons for their lack of preparedness.

Contributing to the lack of supplies was a lack of knowledge. Many people expressed a lack of ability or knowledge regarding how to:

Acquire the money to purchase items

Manage medications that will be needed

Determine with confidence what items would be needed

Problem solve a strategy to manage such a large task

Many people indicated that the task of 'becoming prepared' seemed to require a significant amount of knowledge, resources, and time and was generally perceived to be a goal that was out of reach.

GAP: Personal preparedness for people with disabilities should be centered around their individual needs and begin with a focus on their individual plan for the situations that may occur in their environment.

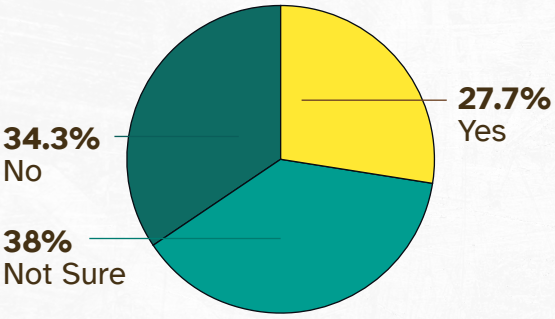
> "I think I'm prepared a little bit in terms of having a go-bag of supplies, things that I need for basic survival, but in reality **I'm not prepared at all because you know, I rely on attendants to assist me with personal care** depending on where I am at the time of the emergency, whether I am in bed or if I'm in my wheelchair. I really wouldn't know what to do for transportation. I do have access to an accessible vehicle, but not all of the time. And just, you know, the logistics of managing my wheelchair getting to a safe space."
>
> —Focus Group Participant

Their preparedness activities should include communications planning, evacuation, transportation and shelter planning, health maintenance planning, emergency resources that support these plans (emergency kits/shelter in place kits/go kits/ etc.), and a routine maintenance practice that ensures the plan is useful.

Few, if any, respondents stated that they had a strategy, process, or guide that they used to create their preparedness plan. Only a few respondents focused on the planning process and indicated that this was an ongoing activity for them. Because most respondents focused on the tangible kits and what must be included in their kits, without having a plan or strategy, the task of 'creating a kit' to 'become prepared' seemed like a large, solitary, and unreachable goal.

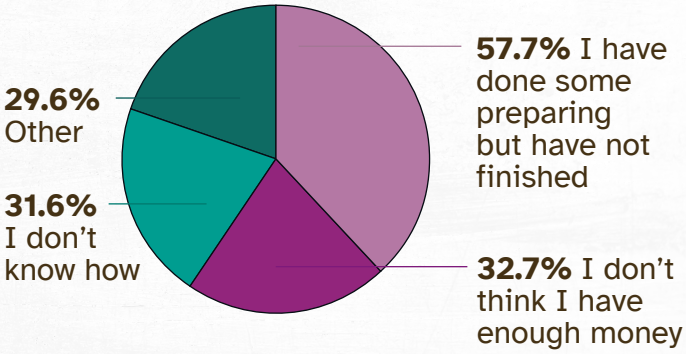
CONSIDERATIONS: How can the County, other public agencies, private organizations, and disability-led organizations get accurate and actionable preparedness information to support people taking action, feeling empowered and informed, and confident in the support that they are receiving to adopt a lifestyle of preparedness?

Are you prepared for a disaster or emergency that might require you to evacuate or shelter in place?



What are the reasons you don't feel prepared?

(Participants chose all that applied)



> "Personally I think everything boils down to financial constraints, you know, and the difficulty in obtaining and affording specialized equipment. I have visual alerting devices because [my son] had the money to do it for me. Actually, I think **we need a community of support[...]organizing peer support groups and online forums [that] focus on financial literacy and empowerment."**
>
> —Focus Group Participant

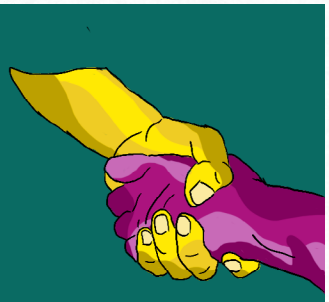
2 Most people who experienced an emergency or disaster were helped by family and friends and expect to receive help from family and friends in other emergency situations. (Expectations & Experiences with Help)

SUMMARY: Regardless of whether or not they had a plan to secure assistance from friends and family during a disaster, the majority of people experiencing an emergency or disaster contacted and received their primary assistance from friends and family for evacuation, transportation, assistance taking equipment and supplies, and for sheltering. This aligns with the experiences of other survivors in other disasters regardless of the disaster or disability.

GAP: Without intentional planning to receive assistance from friends and family during disasters, the disaster experience is at risk of being more difficult than necessary. Advanced communication can address the need for transportation of durable medical equipment, storage of medication and inclusion of other disability-related resources. Of interest is that although there was a large number of people who received assistance from friends and family, there was still a notable number of people who had difficulty getting the assistance that they needed during the disaster experience.

Although relying on friends and family during a disaster aligns with whole community preparedness best practices, creates logical networks of natural support, and is a tendency for people with disabilities, it does not diminish the obligation of local and county agencies to provide inclusive and accessible response programs and services in an emergency or disaster.

There is a wide variety of opinions about what is available and what should be available in a shelter. The diversity of opinions indicated that there is a lack of communication and understanding about the roles and responsibilities of the County, and the County's vendors in a disaster, what can and should be expected and what the community should anticipate receiving from local, county, and state government.



I have good attendants on my team. So those are the primary people for me, but [I know] that they all have other responsibilities as well. **I now need to talk to everybody and say, hey, in the event [of an emergency], what does it take for you to come here?** After you make sure that you and yours are safe. I need to have that conversation with them because they're the best qualified to make sure I'm safe, and I think it needs to be at least 2 people because my needs are very high."

—Focus Group Participant

I use my neighbor because he's close to us[...]This past couple of weeks I was sick and [my neighbors] noticed that my car was in the driveway for days and days, and so they finally decided to check on me[...]There are several seniors in our neighborhood who have disabilities. Even if it's just a small [earthquake] shake, we always check on the seniors the next morning[...] We'll say, oh, I didn't see your kitchen light come on this morning, are you okay in there?"

—Focus Group Participant

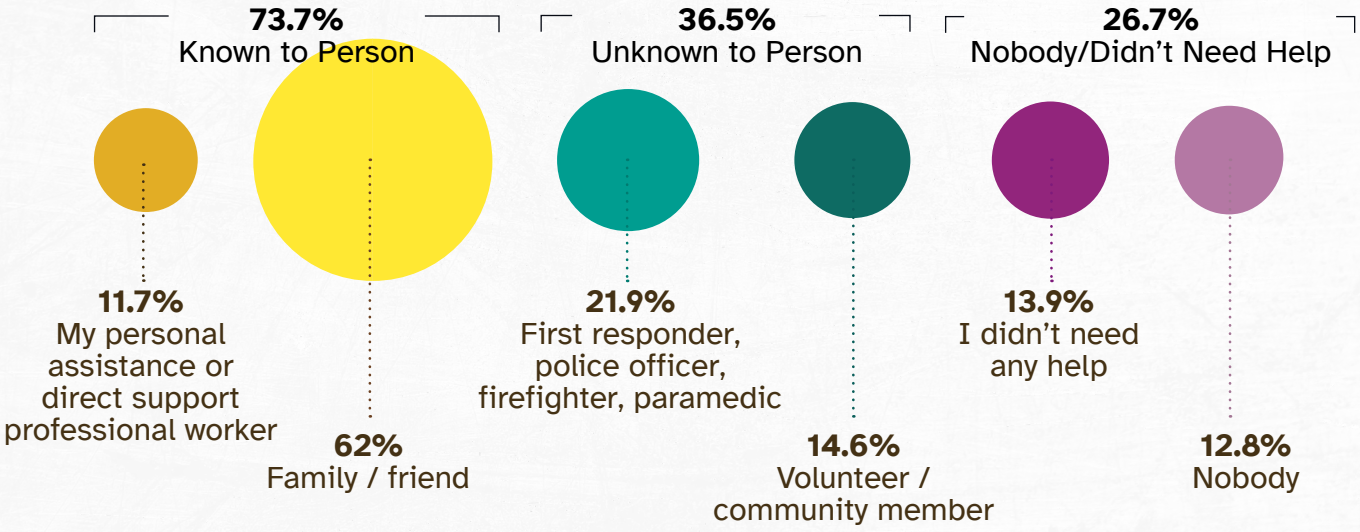
CONSIDERATIONS: How can the County, local municipalities, local volunteer organizations active in disaster (VOADs) and other local NGOs collaborate on effective public information that informs people about response procedures, and roles and responsibilities, so that people have a clear understanding of:

- Their rights
- The response process
- Accurate expectations based on their rights and the response process
- Information on how to collaborate with NGOs and government agencies for improved performance for all
- The value of a whole community empowerment strategy
- Effective partnerships with county resources
- How to plan with family and friends AND benefit from government and NGO assistance
- What a government/NGO fully actualized shelter is

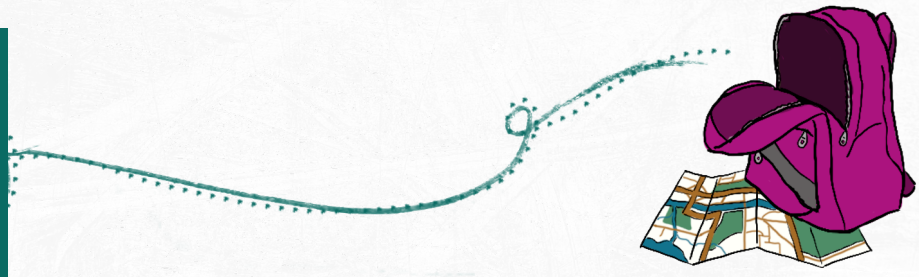
Additionally, how can information about emergency and disaster response and recovery be distributed in a manner that prompts action and dispels fear for people with disabilities, noting that a significant number of people reported that they did not need additional assistance in their lived experience.

Who helped you during the disaster or crisis/emergency experience?

(Participants chose all that applied)



3 The three most significant difficulties for people were: taking necessary resources with them (1), communicating with others (2), and getting the assistance they needed (3). (Experiences with Barriers)



> **I have a lot of specialized medical equipment I need.** It's hard to get enough of it. It's hard to have a place to store it because it's bulky. So I've emptied a lot of the extra stuff I would otherwise need in my go bags."
>
> —Focus Group Participant

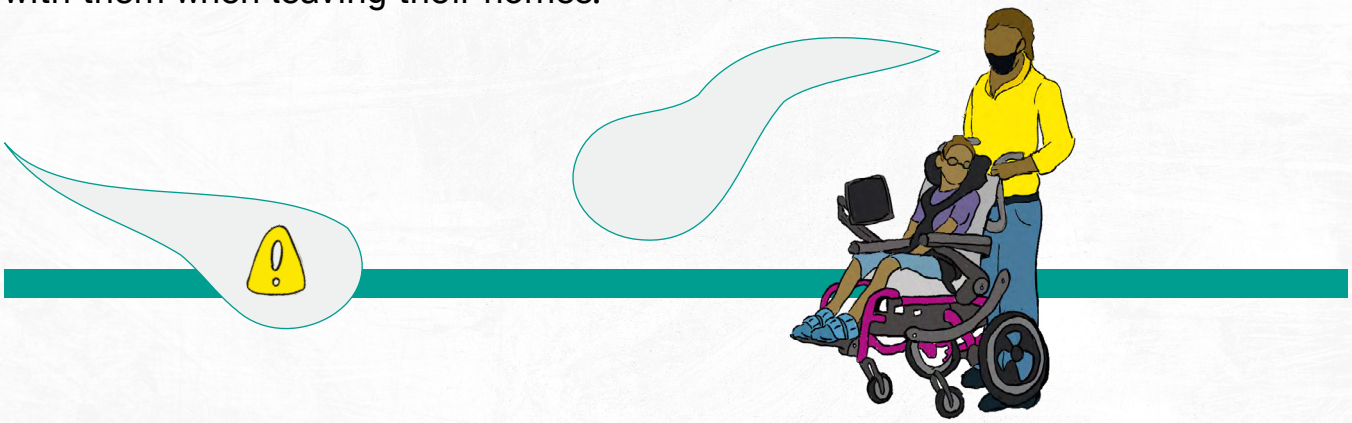
SUMMARY: The experiences of people who experienced an emergency and those who experienced a community-wide disaster were very similar with respect to the negative impact that they experienced. Mental and emotional stress in the form of anxiety, depression, loneliness, and isolation was the most significant negative impact reported by people.

For individuals who experienced an emergency, a significant number of people said that they did not have specific difficulties or challenges. For people who experienced a disaster, the challenges were related to being able to take necessary supplies, resources, equipment and other essentials in an evacuation and the ability to understand information and instructions that were provided to them and simultaneously to provide accurate important information to others during disaster activities in order to get the assistance that they needed.

GAP: Individuals who used durable medical equipment, who relied on public transportation, who lived in multi-story structures, and who had mobility disabilities had difficulties taking their essential supplies with them during the disaster. Contributing reasons for this difficulty were the lack of assistance from others who were available, a lack of resources to make arrangements, including a lack of money to secure assistance or to purchase extra supplies, and a lack of knowledge about how to arrange assistance from programs and services beyond 911.

Difficulties in achieving effective two-way communication with people who were assisting them was a frequently cited challenge. People reported difficulties in both expressing their needs to responders in a way that they felt heard, and receiving the kind of information they needed (sometimes, the concern was a lack of information completely). This appeared to be a challenge regardless of the person's preparedness or who helped them.

People also had challenges getting the assistance they needed. Since a significant majority of the respondents received assistance from friends and family, the lack of assistance appears to be related to the other difficulties taking their equipment, supplies, personal essentials and other disability-related items with them when leaving their homes.



CONSIDERATIONS: How can community members and NGO's effectively communicate with the County to identify the actual needs in the community and assist in collaborating on effective and realistic solutions for providing assistance to individuals to receive the assistance they need regarding evacuation and transportation.

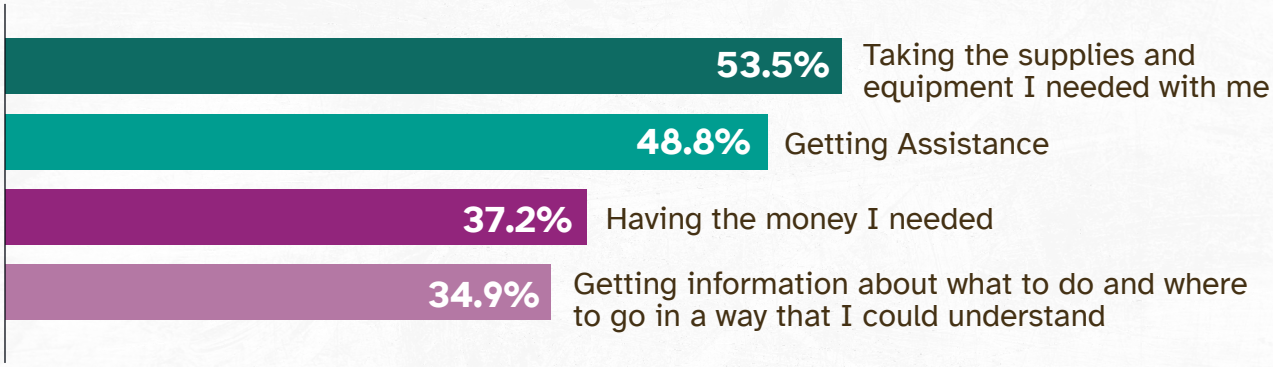
How can community members and NGOs collaborate on achieving effective communication in disaster events between people with disabilities and responding personnel and/or others who might assist individuals.

Specifically:

- The individual's ability to communicate their needs in a stressful environment
- Tools or support materials to facilitate effective communication in the environment for people with disabilities
- Disability competency for responders, friends, and family to understand the unique needs of individuals that they may be assisting
- Tools or support materials for responders and others to be able to use that can assist in facilitating communication

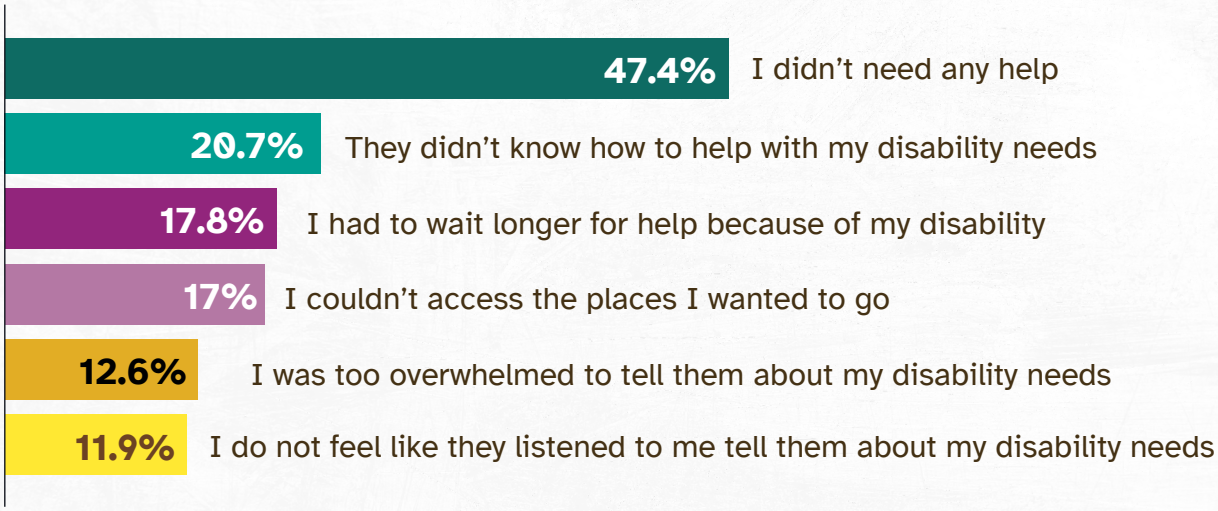
Disaster–What difficulties did you experience maintaining your health, safety, and independence while evacuating or sheltering in place?

(Participants chose all that applied)



When you were interacting with people who helped you, what difficulty, if any, did you have getting your accessibility needs met?

(Participants chose all that applied)



> "I also know to direct people to speak with me when people are ignoring me. And that happens because [I am] very small and I have a quiet voice, and **people assume because of my very visible disability that I'm not intelligent, and like I don't know what I want** [...]"
>
> —Focus Group Participant

4 The majority of negative impacts for people with disabilities that were reported were related to mental and emotional health. (Experiences with Mental and Emotional Health)

Survey respondents wrote in their own answers to the question about a disaster and/or emergencies impact on their health and/or mental health, saying they experienced "general frustration"; "hopelessness"; and "unnecessary pain and suffering."

SUMMARY: A significant amount of time and attention has historically been paid to maintaining physical health and wellness during disasters and in engagements with responders and others. Respondents did not express significant challenges or negative impacts related to maintaining physical health and wellness. However, a significant and consistent negative impact for people was related to mental and emotional wellness and resilience.

GAP: Little attention has been paid to mental/emotional health in personal preparedness training, individual planning, responder strategies, government agency plans, or NGO preparedness strategies for people with disabilities. When mental/emotional health is a part of planning discussions, the focus is on accommodations for people with pre-disaster mental/emotional disabilities or response to emerging mental/emotional impact after the impact becomes evident through survivor behavior. The prevalence of anxiety, depression, and isolation as an overarching impact across disabilities, across demographics, and across emergency/disaster experiences, indicates that there is a communication, understanding and planning gap.

The additional prevalence of communication gaps throughout the responses indicates that communication gaps may contribute to this gap; particularly related to an overarching social gap in communication related to mental/emotional health and wellness.

> "You know, I think because during emergencies [there is] the time pressure and the stress, it's a fast-pace and high-pressure situation. **It can be very challenging for me to communicate because of…the heightened emotions, urgency and confusion."**
>
> —Focus Group Participant

CONSIDERATIONS: How to integrate mental and emotional health and wellness into:

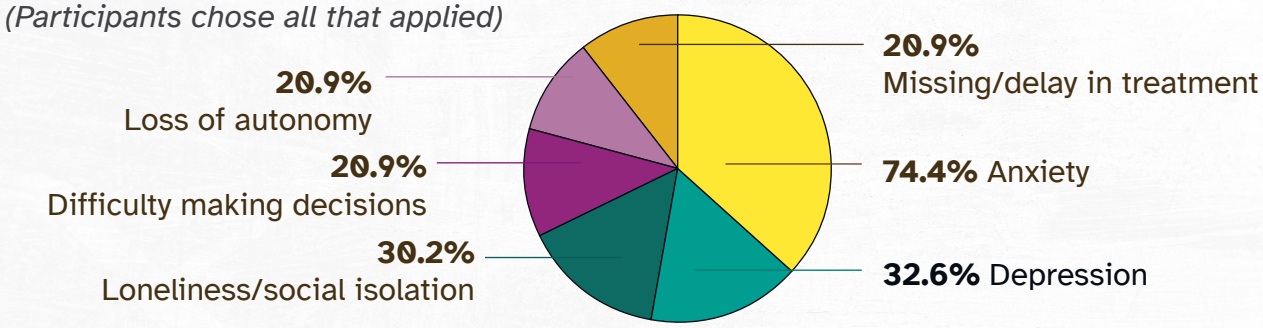
- Personal preparedness planning
- Organizational competencies and emergency planning
- Government agency competencies and training
- Government agency roles and responsibilities
- All conversations related to disability inclusion in emergency and disaster planning, response and recovery
- Whole community strategies to disability-inclusive disaster response

How to integrate mental and emotional health into disaster planning as a health and wellness target for the whole community in addition to:

- Behavioral health planning responsibilities to meet the needs of people with pre-disaster mental, emotional, behavioral, psychosocial or other related invisible disabilities
- Behavioral health planning responsibilities to meet the needs of people with disaster-initiated mental, emotional, behavioral, psychosocial, or other related invisible disabilities

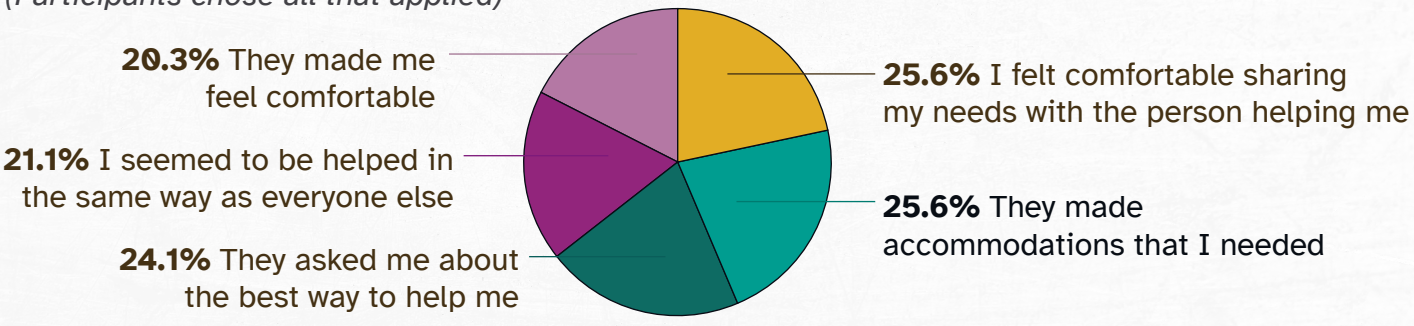
Disaster–What negative impact did you experience on your health and/or mental health as a result?

(Participants chose all that applied)



What went well in terms of meeting your disability needs?

(Participants chose all that applied)



5 Conclusion

As facilitators of this community-driven process, CIL and WID have collected a great deal of information about the experiences, expectations, and challenges of people with disabilities related to disasters/emergencies in Alameda County. We hope that the data, summaries, and most importantly, stories we have gathered here will help open new possibilities for people with disabilities to contribute to and lead in the fields of disaster preparedness and resiliency, whether that be embedded in emergency management, or disability-centered organizations and spaces, or through grassroots and mutual aid/neighborhood networks. We also hope that this report, and all that follows it, will impact the way first responders and emergency management staff understand accessibility and center the needs of people with disabilities before, during, and after disasters and emergencies.

Based on the experiences and gaps identified in the survey data and focus group discussions, the following next steps aim to improve emergency preparedness, response, and recovery outcomes for people with disabilities in Alameda County:

1. DEVELOP AND PROMOTE COMPREHENSIVE PREPAREDNESS PLANS

To address the lack of a clear understanding of what preparedness entails, preparedness education needs to go beyond a focus on the creation of emergency kits. Alameda County can focus on empowering individuals with disabilities by developing resources and training–especially alongside community-based organizations–that promote holistic emergency planning that is integrated into daily living. These plans should include:

- Communication planning: Ensure that people know how to establish and maintain communication during emergencies with critical sources of information and networks of support.
- Evacuation and transportation planning: Collaborate with transportation services to provide guidance and resources tailored to individuals' specific needs and that aligns with local government plans.
- Health/Disability planning: Offer resources and education on managing medications, durable medical equipment, assistive technology, and other essential health needs.
- Routine plan maintenance: Encourage individuals to regularly review, practice, and update their preparedness plans to ensure they remain relevant and can be acted on.

2. FOSTER STRONGER NATURAL SUPPORT NETWORKS

Since most people relied on family, friends, and neighbors for assistance during emergencies, strengthening these natural support networks is an essential recommended practice. Alameda County, local governments, and community-based organizations should:

- Provide educational resources and community forums to help people with disabilities identify and communicate with potential support networks in advance of emergencies.
- Encourage community-wide preparedness strategies, such as neighborhood preparedness groups or disability-specific preparedness networks.
- Assist individuals in creating agreements with friends, family, and neighbors for specific support during emergencies, including transportation, evacuation, and shelter.

3. IMPROVE PUBLIC INFORMATION AND COMMUNICATION

There is a clear need for improved public information regarding what people with disabilities can expect from local government services during an emergency. Alameda County should:

- Develop clear, accessible public education campaigns that communicate the roles and responsibilities of the County, first responders, non-governmental organizations (NGOs), and shelters during disasters–especially as many community members were uncertain about what would and wouldn't be provided at a disaster shelter.
- Create partnerships and MOUs with community-based organizations, particularly organizations that have disability inclusion expertise, to share accurate and actionable preparedness and response information, reaching people with disabilities through multiple accessible channels.
- Prioritize universal access that is inclusive of disabled people, and clarify expectations related to shelter physical, programmatic and communication accessibility, accessible transportation, and emergency response protocols and practices, in their documents.

4. ADDRESS GAPS IN EVACUATION AND TRANSPORTATION

Evacuating with necessary supplies, equipment, and personal essentials remains a challenge. To address this, the County and local governments should:

- Create accessible transportation plans in collaboration with local public transportation agencies and cross-disability communities, ensuring that

the vehicle assets are an accurate representation of the actual community needs related to number, type, and availability of vehicles; and ensuring that the routes, pick up locations, and drivers are able to accommodate people with mobility needs, medical equipment, and other disabilities that may require accommodations or assistance.

- Establish partnerships with private transportation services, personal assistance services, and volunteer networks to provide additional support for individuals who need assistance evacuating.
- Promote the importance of pre-disaster coordination with transportation services in public information to ensure that individuals with disabilities know how to request help during emergencies.

5. INTEGRATE MENTAL AND EMOTIONAL HEALTH INTO PREPAREDNESS AND RESPONSE PLANS

Mental and emotional health impacts, such as anxiety and isolation, were the most frequently reported negative impacts during emergencies. Alameda County should:

- Incorporate mental health maintenance and support into personal and community preparedness planning. This includes encouraging the inclusion of mental health strategies in individual preparedness plans.
- Partner with mental health providers and write these partnerships into response and recovery plans to ensure that emergency response plans include immediate and accessible mental health services, both during the response phase and in short- and long-term recovery.
- Develop public messaging campaigns that destigmatize mental health experiences and encourage people to seek support before, during, and after disaster events.
- Provide mental health awareness training and technical support to County responders and vendors increasing their capability to competently and proactively respond to mental and emotional needs within the impacted community, to include people with pre-existing and disaster initiated mental health disabilities.

6. STRENGTHEN COLLABORATION BETWEEN GOVERNMENT, NGOS, AND THE DISABILITY COMMUNITY

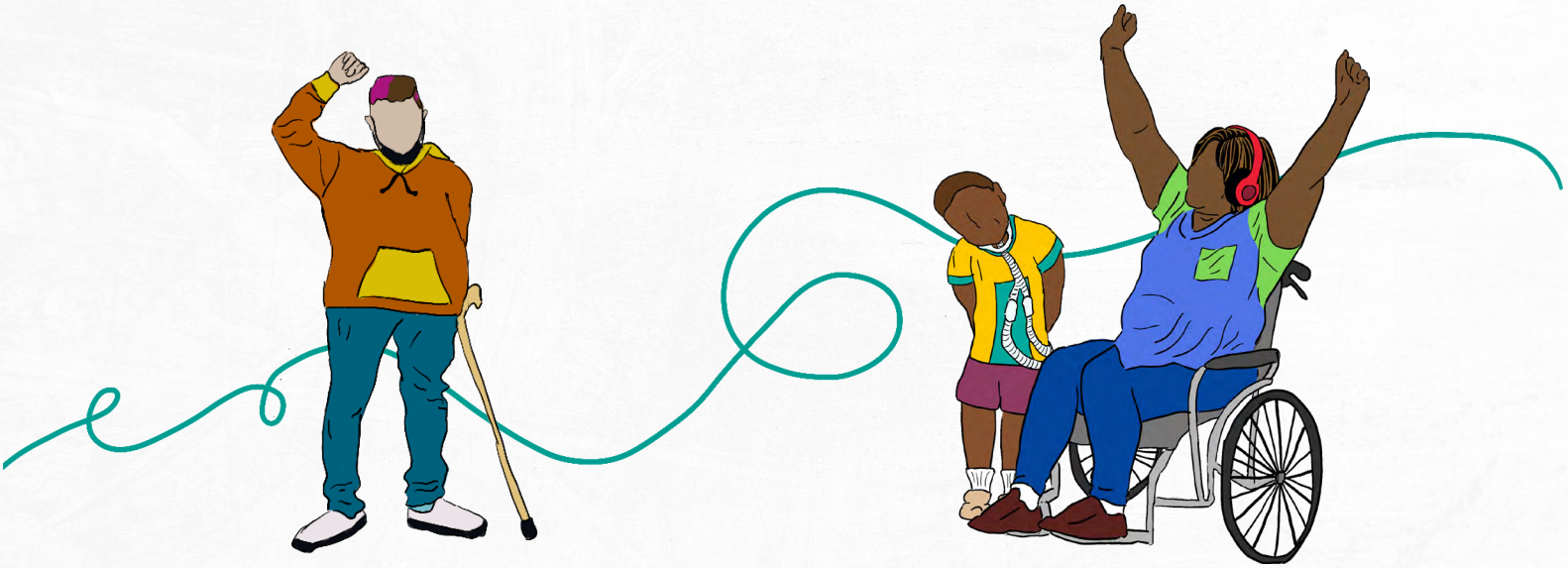
To improve overall disaster preparedness, response, and recovery, the County should:

- Foster strong equitable partnerships between government agencies, local volunteer organizations, and disability-led community-based organizations to create inclusive response strategies through stakeholder groups, coalitions, and community meetings.
- Engage people with disabilities directly in the planning and policy-making processes to ensure that emergency plans reflect their needs and experiences, through inclusion as planning or policy development team members, technical assistants, consultants, evaluators, and exercise participants.
- Develop a County specific survey for emergency managers, planners, first responders, and their affiliate agencies and partners to assess specific gaps in their knowledge of the needs and assets within diverse disability communities during disasters; and aligning the survey with the current body of knowledge in this area.
- Collaborate with disability-led organizations to develop and deliver regularly scheduled and just-in-time disability competency training that addresses the gaps identified in previous research and responses, in this project and in the County provider survey.
- Include disability-led organizations and stakeholders from within the County in planning, development and execution of table-top and full scale exercises; ensuring that exercises are an accurate depiction of the County disability demographics, integrate disability-specific scenarios, and include experts with disability and emergency management knowledge within exercises where possible.

By exploring some of these next steps, Alameda County, local governments, and community-based organizations can build a more inclusive and resilient emergency preparedness, response, and recovery system, ensuring that people with disabilities have the resources, knowledge, and access they need to stay safe during emergencies, disasters, and crisis.

“I don’t know anything in the disability community that doesn’t assist everyone in terms of greater access, greater ease.”

– Focus Group Participant



Glossary

ableism: The discrimination of and social prejudice against people who are perceived to be disabled, based on the belief that typical abilities are superior; rooted in the assumption that disabled people require "fixing" and that people are defined by their disability(ies).

Access and Functional Needs (AFN): The assistance, accommodations and modifications that individuals may need before, during, or after an incident. It may include assistance maintaining health, independence, communication, transportation, and safety. People with access and functional needs may include people who: have disabilities, live in institutionalized settings, are seniors, are children, are from diverse cultures, have limited English proficiency or are non-English speaking, are pregnant, recovering from an injury, or are transportation disadvantaged.

accessible: A person with a disability is afforded the opportunity to acquire the same information, engage in the same interactions, and enjoy the same services as a person without a disability in an equally effective and equally integrated manner, with substantially equivalent ease of use; the person with a disability must be able to obtain the information as fully, equally, and independently as a person without a disability.

accessible transportation: Transportation assets and services that are suitable for people with disabilities and others with access and functional needs. It includes vehicles, vehicle features, embarkation points, communication and information systems, and assistance and accommodations that facilitate consumer use.

accommodation: Also referred to as a "reasonable accommodation"; a modification or adjustment to a job, the work environment, or the way things are usually done during the hiring process; these modifications enable an individual with a disability to have an equal opportunity to get a job and successfully perform their job tasks to the same extent as someone without a disability.

alternative format: A document in large print, Braille, printed on colored paper, a paper copy of an electronic resource or vice versa, or an electronic resource in an alternative way, that provides equal access to information for people who are blind or low-vision.

American Sign Language (ASL): The most commonly used sign language in the United States.

Assistive Technology (AT): Any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities; examples are screen readers, screen magnifiers, voice recognition software, and selection switches.

barrier: A condition or obstacle that prevents individuals with disabilities from using or accessing knowledge and resources as effectively as individuals without disabilities; can be attitudinal, organizational or systemic, architectural or physical, information or communications, or technology.

B/blind: Unable or nearly unable to see because of injury, disease, or a congenital condition; legal blindness is considered a central visual acuity of 20/200 or less in the better eye with correction, and functional blindness is having to use so many alternative techniques to perform tasks that are ordinarily performed with sight that the person's pattern of daily living is substantially altered.

Braille: A system of writing or printing, devised by Louis Braille for use by the blind, in which combinations of raised dots or points are used to represent letters, characters, and so on, and are read by touch.

captioning: Can refer to automatic speech recognition (ASR) captions, CART, or hybrid versions, e.g., Hamilton Web CapTel service where a live person, called a communication assistant (CA), repeats into speech-to-text technology what one party in the conversation says.

Communication Access Realtime Transcription (CART) captioning: Real-time speech-to-text service provided by live captioners.

cognitive disability: Also referred to as "intellectual disability" or "cognitive impairment"; a term used when a person has certain limitations in mental functioning and skills, such as communication, self-help, and social skills; can be caused by injury, disease, genetic condition, or a brain abnormality.

d/Deaf: When used with a lowercase "d," it refers to individuals with partial or total hearing loss and little to no functional hearing who prefer oral communication. When used with an uppercase "D," it describes people who identify as culturally Deaf and are actively engaged with the Deaf community.

dexterity disability: A disability that affects a person's fingers, hands, wrists, and/or arms; it can be caused by a wide range of illnesses and accidents, such as carpal tunnel syndrome, arthritis, stroke, Parkinson's, cerebral palsy (CP), multiple sclerosis (MS), loss of limbs or digits, spinal cord injuries, and repetitive stress injury, among others.

developmental disabilities: Disabilities that are physical, mental, or a combination of physical and mental disabilities of children age 5 and over and that manifested before age 22 and are likely to continue indefinitely and result in substantial limitations in three or more of the following major life activities: self-care, receptive or expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

disability: Any condition that impacts the ability of a person to do certain activities or effectively interact with the world around them, socially or materially; these conditions may be physical, sensory, neurological, cognitive, developmental, intellectual, mental, or a combination of multiple factors and may be present from birth or acquired during a person's lifetime; these conditions may be temporary or permanent; disability is an evolving concept.

disaster resiliency: Is the capacity of individuals, communities, businesses, institutions, and governments to adapt to changing conditions and to prepare for, withstand, and rapidly recover from disruptions to everyday life, such as hazard events.

durable medical equipment (DME): Equipment used by an individual on an everyday, periodic, or extended use to maintain their health, wellness and/or independence. Examples of DME include: oxygen equipment, wheelchairs, walkers, hearing aids, C-Pap machines, a white cane, transfer boards, or bariatric beds.

Emergency Operations Plan (EOP): A document that outlines how a government or private entity will respond to a disaster or emergency. It defines how an organization will function during the mitigation, preparedness, response and recovery phases of an emergency, and describes the overall authority, roles and responsibilities, and functions performed by each entity during an incident.

emergency preparedness: The continuous effort of planning, organizing, training, equipping, exercising, evaluating, and taking corrective action in an effort to ensure effective coordination during incident response.

Hard of Hearing: Someone who has hearing loss but with enough functional/ residual hearing that an auditory device, such as a hearing aid, cochlear implant, or FM system, can provide adequate assistance to process speech and sound.

hazard mitigation plan: A strategic framework developed by governments, organizations, or communities to reduce or eliminate the long-term risks and impacts of natural and man-made hazards.

inclusion: The active and intentional act, practice, or policy of providing equal access to opportunities, resources, spaces, organizations, activities, processes, and so forth, for people who might otherwise be excluded or marginalized, such as those with disabilities.

large print: Also called "large type" or "large font"; refers to the formatting of a book or other text document in which the typeface (or font) is considerably larger than usual to accommodate people who have low vision; frequently, the medium is also increased in size to accommodate the larger text.

low vision: Having vision loss that cannot be treated by glasses, contacts, surgery, or medication.

marginalized: When a group of people are ignored by society, treated as lower status, and/or excluded from basic human rights.

mental health disability: A medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others, and/or daily functioning; common examples include anxiety, depression, Ehlers-Danlos syndrome (EDS), obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), and schizophrenia.

mobility disability: Any condition that limits a person's ability to walk, ambulate, or maneuver around objects, or to ascend or descend steps or slopes.

physically accessible: A facility or place that people with functional/ mobility disabilities, may readily enter, leave, and circulate within, and in which they can use public restrooms and elevators.

plain language: A style of communication that prioritizes easy-to-read, concise, and clear information; it is particularly helpful for people with cognitive and learning disabilities.

points of distribution: Centralized locations in an impacted area where survivors pick up life-sustaining relief supplies following a disaster or emergency.

risk assessment: A process that evaluates the potential impact of threats and hazards on a person or population group, to measure the potential for loss of life, injury, economic damage, and property damage.

sign language: An expressive language that uses gestures with the hands, arms, head, face, and body to communicate; there are over 300 different sign languages in the world, varying from nation to nation, including American Sign Language.

WCAG: The Web Content Accessibility Guidelines (WCAG), developed by the World Wide Web Consortium, are considered the universal technical standards that help make the digital world accessible to people with disabilities and meet legal compliance for accessibility outlined in the Americans with Disabilities Act, the Rehabilitation Act, and other laws.

TTY: A teletypewriter, is a device that helps people who are deaf, hard of hearing, or have a speech impairment use a phone to communicate.