

# BEYOND CHECKING BOXES

Findings of the 2019  
Oregon Inclusive  
Emergency Planning (ORIEP)  
Initiative Focus Groups

Submitted by  
Nyla McCarthy,  
Community Engagement Design  
and Facilitation

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*“And it won't take long  
It won't take too long at all  
It won't take long, and you may say  
"I don't know how to be a part of what you're talking about,"  
And it makes me want to say, "Come on!"*

*Ferron,  
From the Album Shadows on a Dime*

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*“It does not require many words to speak the truth.”*

*Chief Joseph*

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Rest assured, dear sisters and brothers, despite your past experiences or fears, you are not boxes to be checked off. You are leaders and pioneers in a growing movement!

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*“Have a sense to look at yourself and say, “Well, wait a minute.  
I’m stronger than I thought I was.”*

*Maya Angelou*

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## Executive Summary

While it is true that significant gains have been made across society to improve the overall quality of life for people with disabilities (passage of the Americans with Disabilities Act (ADA), new assistive technologies, policies mandating captioning of video and film, the increased prevalence of curb cuts in urban areas, incorporation of features of Universal Design by cutting edge architects, funding for personal assistants, etc.), one area that is only now beginning to catch up is the provision of disaster planning and response.

In fact, gap analysis research on this issue has revealed significant inconsistencies across jurisdictions related to the incorporation of structured inclusive planning processes in emergency operations centers (Los Angeles County Department of Public Health, 2017). Research across the globe has identified that improved first responder knowledge, as well as positive, pre-existing community relationships, are the critical foundations to successful implementation of genuinely inclusive emergency response.

In Oregon, there is hope and forward progress. Oregon is proactively undertaking a significant culture shift in its planning for, and implementation of, emergency management.

An initiative began in 2018 through a partnership with key players from across the service delivery spectrum. That work group, spearheaded by leadership within the Department of Human Services (DHS), Oregon Health Authority/Oregon Public Health (OHA PH), the State Independent Living Council (SILC), Oregon Office of Emergency Management (OEM), and most critically, disability service organizations led by people with lived experience of disability, combined efforts to set the ground work for building inclusion in emergency management.

Specifically, the work group identified two major objectives:

1. Provide a statewide forum for disability communities and emergency managers on best practices for integrating persons with disabilities into the emergency management planning process, to be held June 18, 2019
2. Establish a Statewide Disability Advisory Council for Oregon to formally convene following the June 18 forum

Seed funding was dedicated to the initiative. Activities were launched using a tiered, mixed methods approach – identification and selection of agency professionals to coordinate the inclusive planning approach internally, and the engagement of a culturally competent, public involvement facilitator to design and implement a grass roots recruitment and partnership campaign.

As North Star, the work group embraced the core value of fully integrating people with access and function needs into emergency preparedness efforts throughout the state.

The facilitator, Nyla McCarthy, conducted focus groups with people with disabilities in five locations across the state in order to gain a better understanding of priorities to be discussed at the statewide workshop. These focus groups were sponsored by local partners and employed a cross-disability and intersectional approach. She also held a focus group with emergency managers at the annual Oregon Prepared conference.

Several primary themes emerged from the focus groups:

1. Outreach is needed to increase understanding of the purpose of emergency management services and the capacity to provide these services within each community.
2. There is a desire both among people with disabilities and among emergency managers to expand their knowledge, education and training on topics such as personal preparedness, risk communication strategies, and learning the language used by the other group.
3. People with disabilities and emergency managers expressed the essential nature of trust in this work and the need to repair community relationships damaged by previous incident or emergency shortfalls.
4. How the work is done will be important. Sharing power and decision-making responsibility with community members, ensuring people with disabilities hold the majority of seats on the Disability Advisory Council, being intentional about equity among Council members, and allocating adequate resources (funding and staff time) are critical to the success of this effort in the future.

A detailed list of recommendations for the Inclusive Emergency Planning Workshop has been drafted based on these key themes. All recommendations are intended to make the workshop itself a positive and fruitful experience for all attendees, placing the experience of people with disabilities at the forefront. The workgroup is incorporating these recommendations into the development of the workshop agenda.



## Focus Group Design and Preparation

### Background

In January 2019, the Oregon Public Health Division's Health Security, Preparedness and Response Program, the fiscal oversight entity for the ORIEP Workshop, contracted Nyla McCarthy to serve as architect and facilitator of a community outreach and public involvement initiative, culminating with the establishment of a statewide Disability Advisory Council for emergency services planning within the state of Oregon.

The facilitator submitted a draft work plan for comment and review. It was amended to reflect feedback, including the short time frame available for completion of a comprehensive, representative, grass roots public involvement campaign, with the reality of limited financial resources currently available, to support the initiative and activities to follow. This work plan was created to support a root cause analysis, supported by seven (7) deliverables, designed to maximize limited funding for the greatest possible outcome.

The seven deliverables were designed in support of a commitment to ensure outreach and inclusion of the most disproportionately impacted individuals across the state, moving well beyond players who live within urban reaches of the Willamette Valley who might be most often selected for participation in research projects or citizen committees/advisory groups.

The aim was, and is, to identify and empower new and emerging leadership within communities of people who live with disabilities, particularly communities of color, the rural poor, immigrants or those with limited English proficiency, sexual minority community members, and those who have not experienced bureaucratic enculturation. As a person with disabilities, the facilitator's ethic is driven by a commitment to the disability justice model and human rights.

This approach allowed her to connect with, and organize among, many grass roots organizations and individuals in rural and small-town Oregon who traditionally harbor distrust of government, feel left out and underserved, and serve themselves as gateways to the voices that must be heard. The ultimate goal was to reach those most likely to be negatively impacted in catastrophic and emergency situations, those most likely to be left behind.

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*Alis Volat Propriis*  
*(She flies with her own wings)*

*Motto of the State of Oregon*

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## Project Deliverables

1. Project orientation and focus group planning
2. Conduct 3-5 focus groups (one was added with emergency managers from across the state) to locations outside Portland/Salem
3. Compile and present report on focus group findings
4. Full day workshop planning
5. Finalize workshop details
6. Facilitate full day workshop
7. Compile and present report on recommendations derived from the workshop, specifically those relating to membership of the formal Advisory Council and its potential work plan

## Statement about Approach

After meeting with the workgroup leads, the facilitator familiarized herself with research and online background material related to the history of disproportionately impacted individuals in emergency and catastrophic situations, both globally and within the United States. She sought out the most comprehensive studies thus far conducted in the state of Oregon.

The aim was to explore information already in existence closer to home with a desire not to discount previous attempts, but instead, to build upon those efforts. “Developing a Culturally Specific Emergency Communications Plan for the Disability Community, Final Report,” produced by Women With Disabilities Health Equity Coalition (WowDHEC) (Project Investigators: Marjorie McGee, MS, LPC, Sara Beth Weiner, MSW, MPH, Michelle Berlin, MD, MPH, and Roshanthi Weerasinghe, MPH), 2008 is one such document. It is filled with detail and excellent information for the Advisory Council’s future planning purposes.

## Questions

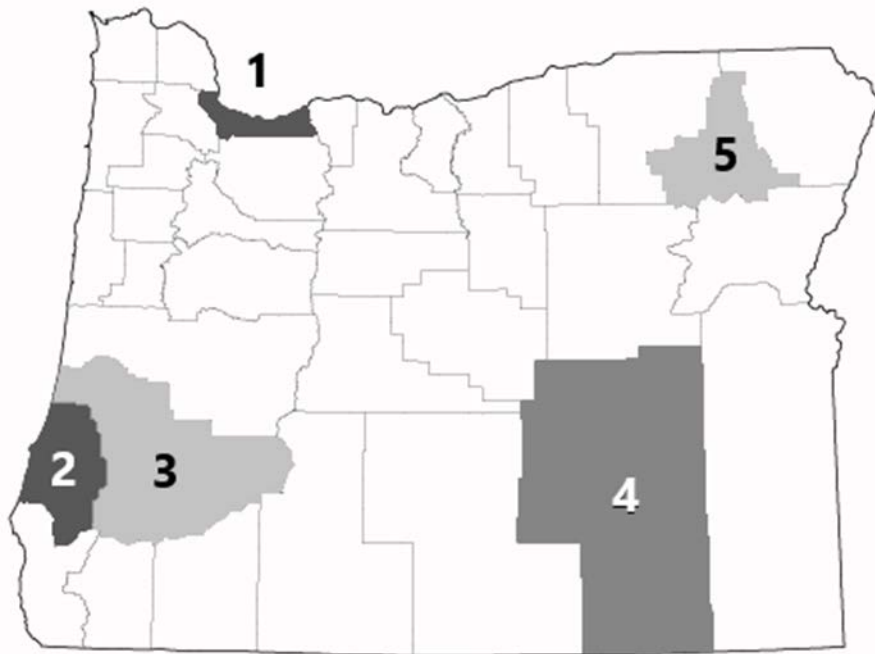
Using insights gained from this research, five topic areas were developed for discussion:

1. What do you consider to be an emergency?
2. When you hear “Emergency Management,” what does that mean to you?
3. What questions do you have about the emergency management system in Oregon?
4. During emergencies, the needs of people with disabilities are often not fully understood. If you could tell emergency managers one thing, what would that be?

5. If you were attending a workshop to figure out how to have better partnerships (and collaboration) between communities with disabilities, emergency managers, non-governmental organizations and local first responders, what topics would you expect to be discussed?

Additionally (time permitting), the question, “Do you have an Emergency Go Kit?” was added for a show of hands during wrap up. (Note: this proved to be an illuminating question, emerging as one of the top recommendations for topics for the June forum.)

## Locations



The following locations were identified for the focus groups:

### *1. Multnomah County*

As the largest metropolitan and population area of the state, with a population of nearly two million in the larger greater metropolitan area according to Prosper Portland 2, 2019, the City of Portland alone is home to an estimated 180,000 persons living with disability. Additionally, 11% of this population (19,800) identify as Latinx or Hispanic, 6% identify as African American (10,800), 7% identify as Asian (12,600), and slightly less than 1% identify as mixed race (1800).

15% of Multnomah County’s population (27,000) are newcomers (immigrants and refugees), predominantly from (in order of population count) Slavic countries, Vietnam, Laos, Cambodia, Cuba, and Somalia. (“In Need of a Long Welcome, Supporting the Integration of Newcomers to Portland”, Center to Advance Racial Equity, Portland State University, 2016)

## *2. Coos County*

With a population of 64,000, Coos County was once home to one of the largest international shipping ports in the United States (Port of Coos Bay) and a thriving timber economy. Now, more than 16% (10,560) live below the poverty level, with veterans, the homeless and temporarily un-housed, and households headed by single mothers contributing significantly to that statistic. One in three children in the county live in poverty.

It is estimated that 12,800 people who experience disability live in Coos County, with a large number of unserved individuals living uncounted and off the grid. 90% of Coos County residents identify as white, with the Latinx/Hispanic population at 7% and First Nations/Native Americans nearly 3%. Over 14% are registered veterans, higher than the state average. 62.6% (40,064) of the county is either on Medicaid, Medicare, or both (Coos County Health Assessment, OHA, 2017).

## *3. Douglas County*

As of the 2010 Census, 107,690 people lived in Douglas County, the fifth largest county by land size within the state of Oregon. Approximately one fifth of those live in the City of Roseburg (21,660), with the majority living throughout the hundreds of unincorporated hills and valleys of the county. The entire county is designated a Rural County, by the Oregon Office of Rural Health. A full one third are over the age of 60; additionally, persons experiencing disability account for approximately 24,769 residents, higher than the national or state average.

Following the collapse of the timber economy in 2008, Douglas County has consistently experienced a higher unemployment rate than the national and state averages. 16% percent of the people in the county live in poverty, including one in four children. Douglas County is predominately white (92%). Of the people of color within the county Latinx/Hispanics account for 40% and First Nations/Native Americans account for 15%. Drug addiction and its illicit production are at rates higher than average, as are suicide and depression (Douglas County Health Assessment, OHA, 2017).

## *4. Harney County*

Harney County is the largest county by size in the state of Oregon and one of the largest in the United States. It is, in fact, larger than six U.S. states. Yet, due to its remote location and arid, high desert, topography, the total population numbers only 7,422. 60% of the residents in the county live in the combined Burns/Hines corridor. More than 87% are white. 4% of the county (297) is Native American, with a similar number identifying as Latinx/Hispanic. There is a small, but significant, Spanish Basque community. 1632 of Harney County's 7,422 residents (more than one fifth) live below the poverty line.

The percentage of people experiencing disability is higher in Harney County than the state average, with more than half of those over 60 qualifying for disability services.

## 5. Union County

With a population of 25,758 in the 2010 US Census, more than half of the people who live in Union County live in La Grande, the County seat. Union County also has a large population of migrant and undocumented workers for which there is currently no reliable data. Of those within the census tract, 93% are white (23,954), 5% (approximately 1200) identify as African American or mixed, slightly over 1% (240) identify as First Nation/Native American, nearly 1% (225) as Native Hawaiian or Pacific Islander and .8% (206) as Asian.

Union County's population is aging, with over 17% (4413) being over the age of 65. The poverty rate is 16% compared to the Oregon average of 14%. About one fifth of total residents are enrolled in the Oregon Health Plan.

Approximately 4890 individuals are known to experience disability, with co-occurring disorders (including higher than average rates for mental and psychiatric disabilities) being of concern (Union County Community Health Assessment, Center for Human Development, 2012).

### *Statewide Oregon Emergency Managers' Group*

Because it is imperative that we know the thoughts of those in the field doing the work, the facilitator conducted an add-on session at the annual Oregon Prepared Conference in Bend. This workshop brings emergency managers from across the state to collaborate, educate and discuss emerging disaster response issues in Oregon. 13 people attended, with an additional five staff on site. Representation included emergency managers from 9 counties and geographic areas (Coos, Bandon, Malheur, Cow Creek, Sutherlin, Lane, Josephine, Multnomah and Marion), FEMA, the Department of Education, the American Red Cross of Oregon, and OEM.

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*"A government of the people, by the people,  
and for the people."*

*Abraham Lincoln*

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## Recruitment Methodology

The facilitator made 79 contacts, either by phone or email, to individuals and organizations headed by, serving, or representing disproportionately impacted individuals, particularly those experiencing disability.

Additionally, four emails soliciting support from the full work group and two to organizations identifying as stakeholders were sent out requesting help with the recruitment of participants. A few individuals sent out notices to their contact lists. The facilitator received key contact names from work group members, which she followed up in person. In-person contact proves to be the most successful approach for equitable, representative recruitment.

Outreach was focused on recruitment of people who are least likely to be familiar with the policies and procedures of bureaucracy, who are by nature of disability and geographic location less likely to participate in similar initiatives, and who represent a genuine equity of inclusion.

Many professionals who work for organizations or agencies serving people with disabilities expressed a desire to attend focus groups. These folks were reminded that this series of focus groups were designed for individuals with lived experience of disability who do not identify as agency or organizational professionals. It was emphasized that the June workshop is the appropriate place for their input and participation.

### Attendee Demographics

48 individuals attended the five focus groups (not counting the add-on session with emergency managers).

Many of the people in attendance experienced more than one type of disability and many fit more than one category of outreach. Therefore, the numbers below may not match the total number who chose to participate.

In addition to disability self-identifications, 28 of the participants identified as cis-gender female, 17 identified as cis-gender male, one identified as transgender, and two identified as gender non-binary.

Additional categories people used to self-identify included:

- 5 Deaf
- 4 Blind/low vision
- 5 Physical disability
- 2 Quadriplegic
- 2 Paraplegic
- 4 Homeless, or temporarily un-housed
- 5 Parents of children with disability (medically fragile and intellectual/developmental disability)
- 2 Cerebral Palsy
- 6 Mental health survivors
- 1 Traumatic brain injury
- 7 Reporting multiple disabilities
- 4 Non-native English-speaking newcomers/immigrants
- 3 African American
- 3 Latinx/Hispanic
- 4 Asian
- 2 Muslim
- 3 Mixed race

- 4 GLBTQI
- 1 Criminal justice system recent release
- 1 Chronic Pulmonary Disease
- 1 Chronic kidney disease (on dialysis)
- 2 Diabetic
- 2 Seizure disorder/epileptic
- 3 Recovering drug addict
- 4 Survivors of domestic violence (including one male)
- 7 Community professionals who personally experience disability or support a family member who does

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*“The only true disability is the inability to accept and respect differences.”*

*Comic Book Mama*

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# Outcomes

## Key Themes

The following “Key Themes” and quotes are a culmination of the information gathered during the focus group sessions.

### *Theme 1*

The number one theme to emerge consistently among all five groups, echoed within the session with emergency managers, relates to understanding what emergency management services actually are and are not, how to access them, and just what the capacity within each community actually is.

“First of all, we need to know what they can provide. What their immediate plans are for people with disabilities. Then they need to know what we need.” *Multnomah County*

“People don’t know what those services are or how to access them. We take care of each other out here.” *Harney County*

“In our ethnic streams, we don’t know the numbers to call. We don’t go to the mainstream to ask for emergency management. We don’t do 911. Who is on the other side of that line? We don’t know. Back home, government doesn’t love us a lot. Here we expect the same from government. So this creates a serious problem when it comes to serving us.” *Multnomah County*

“I think less than a quarter of us out here actually know what emergency services are even available, let alone how to find out about them.” *Union County*

“It would be great if there was some kind of central location where information about emergencies and services could be kept and updated. I don’t think very many people even know about the tsunami maps, for example. And it’s kind of hard to trust in the officials to share real information.” *Coos County*

“Regular emergency drills would be good. And we need an emergency siren in every community that is accessible to everyone.” *Douglas County*

“Let’s say the cell towers go down. How do we reach them? We won’t have EAS or broadcast capability.” *Emergency Managers Session*

“People who are confined to their homes do not have access to any of the information. They don’t know what emergency is. They don’t know what to do during emergency.” *Multnomah County*



“We need to manage expectations – what we can do and what we can’t do as emergency management. Let’s not overstate capacity.” *Emergency Managers Session*

“I think the first responders and those who work inside the system know what the protocols are for our area, where we should go, etc. but I’m pretty sure the average person doesn’t have a clue.” *Union County*

## *Theme 2*

The second theme running across all sessions, including emergency managers, relates to knowledge, education and training. Individuals with lived experience of disability want to know how to take care of themselves in emergency situations. They want to know what an “Emergency Go Kit” is and how to put one together.

Cultural fluencies, racism, and dominant culture response are issues of grave importance. Strong sentiments were voiced regarding the need for increased disability awareness across the spectrum by all first responders.

Emergency managers echoed these refrains and voiced a desire to learn how to better reach the various populations. Additionally, they articulated a desire to both learn the language of disability and to teach the language of emergency management.

“We need to know how to put together an emergency kit. And self defense. Also, something basic about short wave radios, peer to peer communications.” *Douglas County*

“We need to be able to take care of ourselves. The government is not going to be there to help us. It can’t. It’s not set up that way. Emergency management is Us, managing an emergency to survive until the next day. We have to learn how to do it. Because the cavalry never comes.” *Multnomah County*

“Help people develop skills and plans to shelter in place. And that includes training on proper use of generators and alternative power.” *Harney County*

“Racism out here by first responders is very real. People of color don’t receive fair treatment.” *Union County*

“Don’t pigeon hole individuals in the homeless communities. Some of us have advanced college degrees! First responders have a horrible bedside manner with people who experience homelessness.” *Coos County*

“Learn from the homeless community because they are experts at living with little or nothing.” *Emergency Managers Session*

“What is my top priority? To have a workshop that includes leaders of emergency management from the different areas where we can discuss bias, tokenism, ableism, racism, what else? What it means to actually be inclusive.” *Multnomah County*

“There is a general overall ignorance around Indian Country, sovereign nations, and native peoples’ fears.” *Emergency Managers Session*

“Please present an overview of Oregon Emergency Management, from top to bottom, and everything in between.” *Union County*

“Oh, gosh. There is a real lack of training on disability and a need for it for all kinds of disabilities. Medically fragile. Autism Spectrum. Mental health. The difference between mania and being on drugs. It’s not the same thing. Oh, and Deaf culture.” *Union County*

“I survived the earthquake in Northridge. I’m a survivor of police brutality in Portland due to their inexperience with the deaf. I have a lot I want to see changed. 911 dispatch personnel. Hospital staff. Local Law Enforcement. Emergency Medical Technicians. All the emergency services, be it medical, police, the prison system, jails. There’s just so many gaps.” *Multnomah County*

“Identify and train peer volunteers.” *Emergency Managers Session*

“Why don’t they train up some volunteer squads of just real people? Real people with disabilities who can help one another in disasters, who have been trained in basic first aid, survival skills, and stuff like that.” *Union County*

“Offer information and training on how to deal with people who are in trauma. Help with recognizing the signs and symptoms and proper treatment. PTSD training for everyone.” *Harney County*

“We have to have a workshop on accessibility. I’ve been working with emergency management for over a year. Everybody says next week.” *Multnomah County*

“There needs to be training on how to recognize and communicate with a deaf person.” *Coos County*

“Simulations are really helpful.” *Harney County*

“There should be ongoing weekly columns on emergency preparedness with flyer inserts in all small-town newspapers.” *Harney County*

“Training seems to be done using older and even outdated materials. Maybe that could be fixed?” *Union County*

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*“Education is for improving the lives of others and for leaving your community and world better than you found it.”*

*Marian Wright Edelman*

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### *Theme 3*

The third key theme centered around the issue of trust, evidenced by a history of broken promises, exclusion of people with disabilities from meaningful partnerships, and perceived lack of follow through. Both community members and emergency managers expressed the need to repair community relationships damaged by previous incident or emergency shortfalls.

“How many times do we need to ask our elders and activists to come out and say the same damn thing? How many times do we have to go back to our communities and look like dopes for coming back empty handed? If you don’t have the money to remove barriers to full participation, why are we talking about this? Why are you giving us the impression that we are participating in American democracy when actually all we are doing is participating in free speech?” *Multnomah County*

“Trust is a must.” *Emergency Managers Session*

“Bend is not Eastern Oregon. Neither is Salem. No one ever comes out here to find out what we really think, what we need. But thank you for coming today.” *Harney County*

“It’s so damn frustrating that people in Salem and Portland are the ones making all the decisions for rural Oregon. They don’t have a clue about what life is like or what we really need. Add disability to the mix, and what’s the point on us even talking?” *Union County*

“Homeless encampments will not be reached in emergencies and we got a lot of disabled people, veterans with disabilities, homeless with mental health issues. We don’t trust first responders.” *Coos County*

“When I hear emergency preparedness, I have feelings of frustration, of not being listened to, of militaristic response and our community being shamed... And a lot of that comes from some involvement I had about twelve years ago in emergency preparedness. There was a big snow. And an email went around in our community across disabilities. Non-disabled people were out and about but no disabled people could get out. LIFT could not stop on the sidewalk so people could not get to their appointments. We had meetings about that. Some of those people — I’m going to say it because I am going to be honest...they are still involved in emergency preparedness and they didn’t respond and they weren’t willing to work with us then. So I just feel like I

don't know that I trust doing this kind of work again after all that. Are we just going to be someone's report where they get to mark off the token box that they talked to all of us and we had a meeting? This is not a reflection on you. I want to let you know. It's, is this truly going to be not only our voices are heard, but what we say is taken into consideration and acted upon this time?" *Multnomah County*

"What are their perceptions of what we are already doing? We need to share the facts of what we are actually doing. I suspect we need to be myth busting." *Emergency Managers Session*

"I was involved in a terrible accident and there was blood everywhere. When the ambulance arrived, I communicated I was deaf. The EMT didn't know what to do with me. They didn't know how to communicate with a deaf person. So they knocked me out with an injection. Can you imagine?" *Multnomah County*

"I don't feel safe calling first responders. They just barge in, break doors, bark at you. They need to slow down to assess the situation. Maybe ask, 'Is there anything I need to know?' before taking over. I can't even imagine how bad it will be in a major catastrophe." *Union County*

"If you don't speak English or if you aren't white, you are not treated fairly by government. Not even in a major earthquake." *Harney County*

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*"Trust starts with truth and ends with truth."*

*Santosh Kalwar*

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#### *Additional Themes*

Several additional themes emerged which deserve attention.

- The importance of "Whole Community Response"
- How critical it is that people with disabilities, and disproportionately affected individuals, be recognized as leaders and invited into decision making as equal partners. They should be trained as peer experts for emergency management situations and involved in community response teams.
- Budget and sufficient allocation of resources necessary to support ongoing participation of people with disabilities is critical and must be secured. Without a realistic budget, the initiative will fail, contributing to an even bigger divide between the communities of disproportionately impacted people and government systems. Terminally damaged trust will hinder future engagement efforts.

- The Advisory Council being created should be comprised of at least 2/3 people with lived experience of disability in order to balance power dynamics. Race and cultural equity must be guaranteed. This council of new and emerging leaders deserves to be properly educated in function, scope and roles of citizen councils, leadership skills, decision making models, ethics, realities of state budget process, and small group facilitation skills. The Advisory Council deserves to be properly staffed and funded, including resources for support persons, as needed. Meetings need to move around the state to ensure meaningful participation by those in rural communities. People selected for the council should be “doers,” not just voices or names on a list.
- More people fear, and identify, “catastrophic situations” as active shooter incidents, riots, possible chemical warfare, and other human-caused disasters, than they do natural disasters.
- The number of people who do not have cell phones or regular Internet access is much higher than imagined, particularly in rural and economically blighted areas, where they may only have occasional access via senior and disabled centers, libraries (which generally have limited hours), and occasionally, via coffee houses/cafes.
- Salem was not a popular location for the June event. It was perceived as excluding participation by those most commonly left out. It is suggested that future events be rotated between different parts of the state or located in Bend, which is central, with adequate funding to support participation of the economically disadvantaged.
- The use of technology, video streaming, etc. can be helpful to bring down barriers for those who may have access to it. Captioning must be mandatory on all products created and any events streamed.
- Finding certified sign language interpreters and setting up live captioning on site, especially for rural communities, is extremely difficult. Still, they should be mandatory for events, meetings, etc.
- Focus groups could have been more inclusive if follow up had occurred in time to do outreach to alternative, community-based providers.
- Remote captioning is not an acceptable accommodation for a group of people with disabilities.

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*“Change will not come if we wait for some other person, or if we wait for some other time. We are the ones we've been waiting for.”*

*President Barack Obama*

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## Workshop Recommendations

Each of the locations was ripe with specific training recommendations. The emergency managers additionally surfaced several areas in which they wished to receive more training and coaching, including topics they thought might be of value to community members.

The number and scope of topics identified as potential agenda offerings for the June event was more than could possibly be delivered in one day.

It is crucial these important recommendations are carried forward to the Advisory Council, who will examine ways to most effectively fill them as they develop their work plan.

The facilitator’s fourth and fifth deliverables involve planning the workshop details. After reviewing the wealth of information gathered with conscious use of an equity lens fortified by pragmatic and semantic content analysis, the following recommendations are suggested for a workshop modeling best practices. As possible, these recommendations should be taken into account when developing the workshop agenda.

1. Since the audience will include many people with disabilities, representing a wide spectrum of learning styles and physical limitations, most sessions and remarks will be shorter in length than traditional government conferences. Talking heads will be kept to a minimum.
2. Opening remarks, including logistics and acknowledgements, should be no more than 10 minutes.
3. A short, 10-minute introduction will address to why the workshop was convened and, more importantly, how this day will lead to the implementation of the Advisory Council. Application process for this council should be explained clearly, with deadlines for selection and a date for first gathering/retreat shared.
4. Keynote remarks from a national expert with lived experience of disability, sharing lessons learned from past disasters based on real people and real situations, would be excellent at about 45 minutes.

5. Next, a moderated panel, no more than 60 minutes in length, to share an overview of what the emergency management system in Oregon is, how it is meant to operate, what resources and capacity are actually available, how systems interconnect, and what emergency management cannot do.
6. Be honest about challenges experienced. Use real case examples to illustrate. Ensure visuals accompany the speakers. Ensure at least one person with a visible disability is on the panel. Ensure there is equitable racial and cultural representation. Allow for 10-15 minutes for Q and A with audience. Ideally, this panel will include one urban and two rural emergency managers, the state administrator of OEM, and two representatives of organizations in the field that serve people with disabilities.
7. Include a break after the panel.
8. Re-convene with a session on “Radical Self Reliance for People with Disabilities During Emergencies” co-facilitated by a team consisting of a person with a disability and a person involved in emergency services provision. Ensure that the session is interactive and accessible for all. This is an empowering follow up to the panel. 60 minutes maximum.
9. Extended break, 30 minutes. During this break, which is longer and leads into lunch, people are free to visit the vendors, ask questions, interact and network.
10. Additionally, concurrent 20-30 minute mini workshops or interactive sessions could take place throughout the break in accessible rooms which people may choose to visit. The number offered will depend upon availability of access supports (interpreters, etc.). Topics for these mini-workshops might be selected from the following recommendations: carbon monoxide simulation, a simulation center to experience blindness and deafness, assistive technologies demo, or a short-wave radio demo.
11. Vendors in the vendor room (if one is included) will provide information on a variety of emergency services and models, Emergency Go kits, catalogs and/or brochures about which agencies provide disability services within each region and how to reach them, neighborhood associations and accessible community centers, animal rights and/or adoption, alternative emergency alert systems for in home use, nutrition during times of catastrophe, accessibility tools and supports, first aid, etc.
12. Participants return to main room for lunch following break. Lunch must be plated. Buffet lines are not accessible for a large number of individuals with disabilities and require far too much time for a large group to navigate.
13. After 30 minutes, during which people can eat, chat and network, there is a 30 minute luncheon moderated panel discussion featuring four individuals who experience disability sharing their personal experiences with disasters or emergency situations—

what went wrong and what worked. Choose a panel that represents people with intellectual or developmental disability, the blind/low vision community, deaf culture, those living with mobility disabilities. Balance equitable racial and cultural diversity among presenters.

14. Allow 75 minutes for table-based work group sessions, introduced from the podium as a tool for information gathering for the Advisory Council; each table will then discuss best practices for integrating persons with disabilities into the emergency management planning process. Members of the inclusive emergency management workgroup will facilitate the table groups. Recommendations will be captured and prioritized for reporting back to the full room after a break. Facilitators will support an individual with a disability from each workgroup to be lead presenter.
15. 20-30 minute break to accommodate bio needs and to allow time for informal discussions.
16. 45-60 minutes for work groups to report back, including Q and A. Recommendations will be captured and consolidated, as appropriate.
17. Closing remarks. What comes next, evaluations, appreciation to attendees and organizers.
18. Interactive round of applause for everyone facilitated from front podium. Adjourn.

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*“It’s time to come together,  
Come on! What’s your pleasure?  
Yahoo, it’s a celebration!”*

*Kool and the Gang*

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## Conclusion

After visiting with people from five geographic locations throughout Oregon who not only experience a variety of disabilities, but also live within communities that are economically distressed, the facilitator spoke to scores of people who are used to making do with little while being confronted daily by the differences between those who “have” and people like themselves who usually “have not.”

She listened over and over to folks as they discussed living in areas where racism and ableism are more than just words written into a report such as this, listened to people whose fear and distrust of the government is at an all-time high. She is honored and grateful to have found herself welcomed and treated with respect time and again.

Following a solemn promise made at each session to be always honest and forthcoming, she was humbled by people’s decision to share their stories, their truths, their fears, and their willingness to step up “one more time” if their voices would be heard, their efforts matter.

She was equally impressed by the dedication and desires to make a difference which emergency managers from across the state shared during their annual Bend gathering. Many of those individuals work tireless hours, often underfunded, and in situations where their own lives are put at risk in the service of others. They care.

What all of these groups share in common is a wish to change the way things are now for the better, to keep everyone safe and supported in disasters and emergency situations, to leave no one behind: to learn.

Everyone wanted more than can be possibly delivered in one day – the needs are that great. As a person with disabilities who grew up in poverty, the facilitator understands this desire.

This work represents a rare second chance to keep our promises, rebuild trust, and listen with open mind and heart, as we lift one another up, working to organize, educate, and support the emergence of a new vanguard: a representative Disability Advisory Council of emerging leaders from across Oregon.

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*“Determination, energy, and courage appear spontaneously when we care deeply about something. We take risks that are unimaginable in any other context.”*

*Margaret J. Wheatley*






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# Oregon Inclusive Emergency Planning Work Group 2018-2019

## Leads

- Kristen Darmody Health Equity Planner, Oregon Health Authority (OHA), Public Health
- Anna Feigum Emergency Services Coordinator,  Occupational Health, Safety and Emergency Management

## Members

- Krista Aquinas-Gallagher  Oregon Deaf and Hard of Hearing Services
- Danielle Bailey Disability Integration Specialist, FEMA, Region X
- Emily Cervantes Field Liaison,  Oregon Office of Developmental Disability Services
- Tracy DePew Director of Emergency Management, Cow Creek Band of Umpqua Tribe of Indians
- Marsha Ellis APD Coordinator, DHS Aging and People with Disabilities
- Shelly Emery Operations Coordinator, State Independent Living Council
- Matt Hall  Disability Rights Oregon
- Dawn Helwig  State Independent Living Alliance (LILA)
- Ian Jacquiss Interim ADA Coordinator, OHSU Affirmative Action and Equal Opportunity
- Chelas Kronenberg Principal Executive Manager, DHS Office of Developmental Disabilities Services
- Joseph Lowe Co-Coordinator Oregon Disabilities Commission, Program Analyst for Disability Services Advisory Councils, DHS Aging and People with Disabilities
- Chad Ludwig Interim Director, Regional Resource Center on Deafness, Western Oregon University
- Eileen Marma Oregon Leadership of Hearing Loss Association of America
- Alaina Mayfield  Oregon Office of Emergency Management

Nyla McCarthy	Social Justice and Disability Activist, Project Facilitator
Angela Munkers	APD Field Operations Manager, DHS Aging and People with Disabilities
Kristi Murphy	APD Community Services and Supports Manager, DHS Aging and People with Disabilities
Michelle Patton	Emergency Services Coordinator, DHS Occupational Health, Safety and Emergency Management
Erik Rau	Emergency Management Planner, Oregon Office of Emergency Management
Judi Richards	Advisory Council, Aging and Disability Resource Connection
Hector Rios	ADA Manager, DHS Occupational Health, Safety and Emergency Management
Barbara Robertson	Hard of Hearing Specialist, Oregon Deaf and Hard of Hearing Services
Justin Ross	Community Capacity Specialist, Multnomah 
Sue Staley	Blind Activist, National Commission for the Blind
Fred Steele	Oregon Long Term Care Ombudsman and Agency Director, Oregon Long Term Care Ombudsman's Office
Stan Thomas	Administrator, DHS OHA Occupational Health, Safety and Emergency Management