

2019

»» Oregon Inclusive Emergency Planning Workshop

Summary and next steps
July 2019



Acknowledgments

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Executive summary

An Oregon Inclusive Emergency Planning Workshop was held on June 18, 2019 in Salem, Oregon. This workshop brought together persons with disabilities, emergency managers and disability service professionals. During the workshop, participants:

- Discussed the unique challenges persons with disabilities meet during emergencies, and
- Considered Oregon's opportunities to address these challenges.

A core group of representatives of Oregon Department of Human Services programs; representatives of state, local and tribal emergency management and public health; and individuals with disabilities worked together to plan the workshop. There is not a coordinated approach in Oregon to include disability access in state emergency preparedness and response efforts. State agencies responsible for emergency planning that affect persons with disabilities are as follows:

- Office of Emergency Management
- Department of Human Services
- Oregon Health Authority

These agencies supported the workshop as the first step in a multi-year plan to address the priorities of persons with disabilities in emergency planning efforts. Nyla McCarthy, executive director of Catalysts for Change Institute for Ethical Leadership facilitated the workshop.

The agenda included these presentations and activities:

- Keynote address by Vance Taylor, California Governor's Office of Emergency Services
- Panel discussion on emergency management
- Panel discussion on disability perspectives of emergency
- Table work groups to address specific questions about forming a Disability Advisory Council for Oregon

The table work groups displayed diverse perspectives on:

- How to engage people in the work of the Disability Advisory Council
- Who should be involved in this council, and
- What topics the council should prioritize.

Many thoughtful suggestions to guide the work of the council are listed later in this report. Several themes emerged:

- The experiences of people with disabilities should be the starting point and focus of the council's work.
- Emergency managers and people with disabilities have the opportunity to educate and to learn from one another in a collaborative way.
- Delivering on promises is essential to earning the trust of people with disabilities.
- There is great interest in practical resources for individual planning.
- The council can play an important role in ensuring the inclusion of people with disabilities in drills and exercises.

The facilitator gave analysis and recommendations for the development of the council at the conclusion of the workshop. A summary of the recommendations is below. The full list is found later in this report:

- The Disability Advisory Council should consist of a majority of people with disabilities, with agency personnel in supporting roles.
- The council should be intentionally diverse:
 - » From all parts of the state
 - » Racially and ethnically representative, and
 - » With different kinds of disabilities.
- Special attention should be paid to ensuring rural representation.
- The purpose and function of the council should be clarified before recruitment begins.
- The support of state agencies for this work should be made clear through an interagency agreement. An independent contractor is recommended to manage the first year of the council.
- The application process to sit on the council should be accessible and not bureaucratic in style, in order to engage new and emerging leaders.
- Council recruitment should be underway as soon as possible, preferably by early fall 2019.

The Oregon Health Authority is grateful to all participants for their time, energy, and experiences to elevate this work.

Workshop details

On June 18, 2019 over 140 individuals gathered at the Salem Convention Center for the Oregon Inclusive Emergency Planning Workshop. Besides in-person attendees, 52 people registered to attend remotely. They did so by watching the video stream online or listening via conference call. The event was captioned in real time. Also, ASL interpretation was projected both in the room and on the video stream. Less than 10 percent of attendees requested an accommodation.

Presentations

Summary provided by Nyla McCarthy, facilitator

The day opened with a formal welcoming, brief logistics and opening remarks. These were followed by a keynote address delivered by Vance Taylor from California Governor's Office of Emergency Services. It was well-received. A panel of nine people representing the emergency management system of Oregon, ranging from those at the federal level to the tribal, state and local level, then provided an overview of services and how they work together. The information had been requested by community members. It was described by many as useful and thorough.

The second panel, "Disability Perspectives on Emergency Management," replaced another workshop. That workshop, "Radical Self Reliance for People with Disabilities," was going to be co-facilitated by a multi-racial, multi-abled team. Unfortunately, it was cancelled at the last minute due to personal emergencies of the presenters. The loss was significant and noted by several attendees. Organizers plan to provide material from the workshop to attendees in a future email communication.

The "Disability Perspectives on Emergency Management" panel itself was multi-ethnic and included deaf, blind and physically disabled persons. Their stories were varied. They included both pro-active critiques of and high praise for their experiences with emergency personnel. The primary comment of attendees was a wish the session had been longer. They wished more voices of people with disabilities would have been heard.

The afternoon was devoted to table work groups. Each was assigned one of four questions that were:

- Synthesized from the key themes from the focus group tour, and
- Highlighted in the report, "Beyond Checking Boxes."

Members of the Inclusive Emergency Planning work group volunteered for work

table facilitation, partnering with a table mate identifying as having lived experience of disability, when possible, for the final report out. The majority of attendees were professionals or agency people. Also, there was a lack of persons with disabilities present. Therefore, it became necessary to ask people who were comfortable identifying as having a disability to relocate to tables with no persons with disabilities present. Four individuals said they were happy to do so and moved. However, each of those tables then only had one person with a disability involved in the important conversations. There were also a few tables with no persons with disability present.

Table work groups engaged in deep and robust conversations. In fact, when the 75 minutes for this phase of the activity was over and it was break time, almost every single table continued working, most of them throughout the break. The remote participants also engaged in vigorous discussion. In evaluations, most people commented on this as a high point of their day. They voiced a desire for more time for such activity in future events, with requests for increased representation by persons with disabilities. It is important to stress there were differing opinions voiced by different tables to the same questions. This was often shaped by the demographics of the members of the group. The responses of each group to these questions are below.

Summary of table work groups

Participants discussed the questions below, with each work group starting with one question. Multiple work groups addressed the same question. This produced a variety of ideas and suggestions on each topic.

Question 1: Building upon the recommendations of the statewide focus groups report, what do you think will help ensure the most effective collaboration between your new advisory council and emergency management? How can the council come together in an accessible and inclusive way?

Effective collaboration:

- To encourage effective collaboration between the new council and emergency management, emergency managers should be part of the council.
- Build a feedback loop and get information out in a timely manner.
- The council can help build trust by working with emergency managers to develop a toolkit that can be tailored to the needs of their community.
- Mutual education is necessary. People with disabilities and emergency managers can educate one another about issues that are important to each group. Ask the group what they need. One idea is to provide training for people with disabilities so they can provide emergency services until responders arrive. The council may want to address the issue of engaging people with lived experience of disability to take part in emergency exercises.

- Work is needed to build trust between emergency managers and people with disabilities.
- Some communities have what is known as a COAD: community organizations active in disaster. COADs work with emergency managers. COADs may be a good bridge to ensure inclusion of disability-serving organizations in emergency management.
- The council and emergency managers can coordinate and collaborate on services that overlap.
- The council can listen to real life experiences and use lessons learned to inform their approach.

To build an accessible and inclusive council:

- Meet at least four times per year
- Provide ways for people to take part remotely
- Pay attendees' costs for transportation, caregiving, lodging and meals
- Include people on the margins, such as the very poor, people with behavioral health conditions and rural residents
- For agency representatives, it may help to structure the committee so there are a defined number of seats for representatives of specific organization types
- Make sure there is good communication flow within the council and from the council to the wider community

Question 2: The importance of building trust was listed as a key finding in the statewide focus groups report. With this in mind, who are the most trusted people and organizations/groups in your community when it comes to building bridges between ALL communities of disability? What are some real strategies to building/rebuilding trust with people who have lost theirs?

Trusted organizations include:

- Animal service providers
- Disability service providers and case managers
- Faith-based organizations, especially those serving non-English speakers, people of color, and homeless
- School districts (connection point with immigrants and refugees)
- State Independent Living Council
- Partnership in Community Living
- Love, Inc. (volunteers help with household tasks for people with disabilities)

- Old Mill Center – counseling in Corvallis for people with behavioral and developmental disabilities
- Heartland Humane Society
- Corvallis people of color – NAACP, CASA Latinx
- Fire departments
- Police departments, especially rural
- Community health centers
- Red Cross
- Salvation Army
- Public health departments
- Senior centers
- FACT Oregon
- Disability Rights Oregon
- Oregon Family Support Network
- Deaf advocacy groups
- Resolutions Northwest
- NAMI affiliate
- Neighborhood associations
- Long-term care facilities

Strategies to build trust include:

- Networking with community leaders, advocates and allies to identify and consider a broad range of potential barriers and solutions to meet the needs of their community.
- Take time to learn history, to learn each person's story.
- Share information to support self-determination.
- Increase sustainability and minimize turnover.
- Allocate adequate funding to the efforts.
- Use the Map Your Neighborhood tool to identify community assets together.
- Pay people with disabilities for their expertise.

- Conduct consistent outreach during non-emergencies.
- Partner with people and organizations that can help.
- Try new collaborations.
- Conduct face-to-face meetings and outreach.
- Respect the self-determination of people who have been hurt. Consider what has been tried already and what hasn't worked.
- Set objectives, meet them and produce something tangible beyond just meetings. Follow through with promises.
- Conduct drills and exercises with members of the community to discover barriers not previously known and uncover lessons learned.

Question 3: The number one theme to emerge from the statewide focus groups report related to developing awareness of emergency services. Are you aware of emergency preparedness activities that have taken place in your area? What is the most effective way to communicate to various communities of disability?

Awareness of emergency preparedness activities:

- Very few preparedness activities were identified:
 - » Specific to people with disabilities, or
 - » In which people with disabilities were included and engaged.
- People with disabilities should be engaged at the beginning of the preparedness process, including messaging.
- People tend to get involved when they receive a personal invitation from a trusted acquaintance.
- Including people with disabilities on neighborhood emergency teams would build awareness.
- Support is wanted and needed in training and building relationships with providers.
- There needs to be acknowledgment of the difficulty of encouraging preparedness when some people, especially low income, have a hard time meeting their day-to-day needs.
- Some people feel a sense of invincibility, like disasters can't touch them, which creates a barrier to getting them involved in preparedness activities.
- One inclusive strategy is to train volunteers and first responders to ask, "What do you need?"

- Community paramedicine and mobile integrated health are resources communities can explore as part of their inclusive outreach.
- Support exists for a universal registry for those with additional needs. However, there is concern about privacy issues.
- Preparedness awareness should be about what is relevant to a specific community.
- People can support themselves by building connections with others around them.
- It is important to provide self-sufficiency training and preparedness for people with disabilities, as well as parents and caregivers.

Effective communication with communities of disability:

- Email
- Social media
- Postal mail
- Through advocates and caregivers
- Person-to-person
- Trusted messengers, such as fire departments, schools and faith-based organizations
- Community Emergency Response Teams (CERTs)
- NextDoor
- Flash Alert or other emergency communication systems
- Ask each community how information should be communicated. Ask “what works for you and others with this disability?”

Question 4: Considering recommendations from the statewide focus groups report as simply a baseline, what advice do you have for emergency managers and their staff who are committed to ensuring more involvement and inclusion of people with disabilities in their communities? What do they need to know, what are some challenges and gains, what outreach will be effective?

Advice to emergency managers:

- Emergency managers stand to gain:
 - » More equitable policy
 - » Greater sensitivity
 - » Plans that work for the whole community, and
 - » Re-established trust that can broaden the scope of partnership.
- Find persons with disabilities and ask how to help. People who may not have access to traditional communication methods or those with mistrust of government may be hard to identify.

- Having tangible resources such as a toolkit will help emergency managers build trust.
- Network with community leaders.
- Conduct a needs assessment and then hold seminars or forums on:
 - » Finding people with disabilities, and
 - » Addressing physical or cultural needs.
- Use Vance Taylor’s talk to motivate and educate people.
- Invite FEMA to do technical assistance.
- Pursue a funded mandate to consider access and functional needs.
- Work with schools to develop emergency preparedness plans that encompass the entire school population.
- Take children into account.
- Include people with disabilities in planning for human-caused disasters such as mass shootings.
- Mandate inclusive planning committees at local level, to meet two to three times per year with incentivizing.
- Create a resource document for those with disabilities.
- Provide tools for access and functional needs planning, such as best practices documents.
- Leverage the knowledge of the community as a resource.
- Encourage emergency medical services (EMS) to coordinate with disabled stakeholders.
- Emergency managers should consider:
 - » Who is impacted by disability
 - » How many people are impacted, and
 - » How to find them in a disaster.
- Develop preparedness curriculum specifically for people with disabilities.
- Use frequent and consistent messaging to share important preparedness information.
- Partner with primary care providers.
- Look for opportunities for people with disabilities to engage in activism; for example, lobbying for a 60-day supply of medication rather than 30-day.

- Emergency managers should conduct effective outreach rooted in self-determination, drawing on specific experiences of people in the community.
- Make sure to keep the focus of any community meeting – to be for the people it serves, not for the organizations present.
- Limit the use of jargon.
- Be aware of the diversity of groups – there are many kinds of disability.
- Be willing to learn and change course if necessary.
- Challenges will include:
 - » Overcoming the lack of trust and previous bad experiences
 - » Lean staffing of emergency management offices and organizations serving people with disabilities
 - » Lack of consistency due to staff turnover
 - » Uncertainty about funding, and
 - » The need to encompass all of Oregon in this effort, not just the Willamette Valley.

Evaluations and feedback: major themes

Participants were asked to share their thoughts on the workshop. They gave feedback by filling out paper evaluations on the day of the workshop or by emailing comments to the organizers. Praise and criticism will be considered when future events are planned. Participants gave feedback on the workshop itself and suggestions about how to move forward with the formation of the Disability Advisory Council.

Workshop feedback

Many participants were grateful for the opportunity to gather and explore this important topic. Some expressed disappointment the workshop did not provide specific information how to support individuals during emergencies; while this is an area of great interest, the purpose of the workshop was to lay the groundwork for the Disability Advisory Council, which will have a greater hand in vetting and sharing such practical resources.

Top takeaways from the workshop primarily related to:

- Broadening perspective
- Learning more about barriers and strengths
- Gaining greater understanding of the responsibilities of emergency managers, and
- Gaining greater understanding the priorities of people with disabilities.

People appreciated:

- Energy and enthusiasm of participants
- Networking opportunities
- Effective facilitation, and
- Multiple communication formats (ASL and CART).

Vance Taylor's address was a highlight of the day for many people. His participation was very appreciated.

Several opportunities for improvement were identified as well:

- The day was long; more breaks would have helped.
- Participants strongly stated that they would have wanted more time for questions and discussion and less talking from the stage.

- People wanted to hear more from people with disabilities.
- Participants noticed the emergency management panel was not diverse:
 - » There were no people of color
 - » They were predominantly male, and
 - » None of the panelists identified as having a disability.
- People noticed that attendees tended to sit with people they knew. This led to separation of participants by profession or by experience.

There were many opportunities to improve the variety of what was presented:

- Use of more visuals
- More engaging speakers
- Provide all materials in written format (including discussion reports).
- It would have been helpful to have more time to read the focus group report.
- There were opportunities to improve the physical environment, to make it more comfortable and accessible:
 - » Select more comfortable chairs
 - » Adjust the temperature and lighting
 - » Provide a sensory room with appropriate materials, and
 - » Choose a location closer to where people live.

Moving forward

People expressed great hope and enthusiasm for making emergency management in Oregon more inclusive of people with disabilities. Participants made many suggestions for the work ahead, both in general terms as well as specific ideas for the Disability Advisory Council.

The broad ideas included suggestions for more:

- Gatherings
- Education, and
- Tools and resources.

People called for greater representation and visibility of:

- Children with disabilities
- People of color, and
- Rural Oregonians.

Participants also made specific suggestions for the formation of the Disability Advisory Council:

- First, Oregon should look to other states and other sectors to gain wisdom from their experiences of forming such councils.
- The details of the council’s work and members’ expected participation should be clear from the beginning so that people understand what they are signing up for.
- There is great desire for the council to:
 - » Be creative in its approach and structure
 - » Feel less “stuffy” and governmental
 - » Keep a focus on mission, and
 - » Encourage empowerment.

Recommendations

Provided by Nyla McCarthy, facilitator

In addition to participants' feedback, the workshop facilitator and disability advocate Nyla McCarthy provided an analysis and recommendations for the Disability Advisory Council.

1. Determine the purpose and function of the Disability Advisory Council is going to be before recruitment begins. The council's purpose will impact the training needs and support needs for the new group. Once these decisions are made, the Disability Advisory Council itself can be trusted to develop their goals and objectives in alignment and to create appropriate workplans.
2. There is strong consensus from across the spectrum of stakeholders that the soon-to-be-formed Disability Advisory Council be comprised of a majority of individuals with lived experience of disability. The ideal target remains two-thirds persons with disability and one-third professional or agency representatives.

There was no clear recommendation about the number of council members, but experience shows that in groups with similar demographics, a range between 15 and 25 persons is likely to enjoy the most successful outcomes., Training must be provided to membership so they may work effectively and successfully in arenas of:

- Collaboration
- Decision making
- Conflict management
- How government works
- Budgeting
- Ethics
- Facilitation skills, and
- Public speaking.

3. Persons with disabilities must be recruited from across Oregon to serve on the council. There were many suggestions for which "constituencies" of disability should be recommended with no emerging consensus. However, there is a clear directive to ensure that the group include mental health consumers and that invisible disabilities be represented (example: chronic illness or seizure disorder).
4. Members of the Disability Advisory Council, including persons with disabilities, disability service professionals and emergency managers, must be racially and ethnically representative of the state's demographics.
5. Include rural residents in membership for the Disability Advisory Council, both among those with disabilities and those representing emergency management agencies or disability service organizations. At least half of the total membership should come from Eastern and Southern Oregon and coastal communities.

6. There is emerging consensus in favor of having professionals from the emergency management sector represent both upper management and “on the ground” service providers.
7. There was much discussion, with varying opinions, related to the oversight, or stewardship of the Disability Advisory Council. With that in mind, there is a recommendation for development of a clear interagency agreement between the agencies involved:
 - » Department of Human Services
 - » Oregon Health Authority
 - » Office of Emergency Management

The interagency agreement should address:

- » Roles and expectations
- » Support functions provided
- » Resource allocations, and
- » A clear chain of command, with a single point of contact named as the project lead.

This agreement needs to be in place before the Disability Advisory Council is convened. It is suggested that the Disability Advisory Council be staffed by an independent contractor for the first year. The contractor should work in collaboration with state and agency personnel to develop a succession plan for the council.

8. Create an application process and selection process for the Disability Advisory Council is accessible and not bureaucratic in style. The process should embrace recruitment methodologies that allow new and emerging leaders to receive consideration. Allocate appropriate time and staffing to engage in person-to-person outreach to achieve this goal.
9. Stan Thomas delivered a clear and eloquent description from the podium of why timelines may be frustrated when it comes to convening the Disability Advisory Council. Summer is a busy season and fires consume the time of already stretched personnel. Still, we heard from the community that it is critical not to let too much time lapse before implementation. Recruitment should be underway by late September.

Next steps

There are three major efforts that form the next stage of this work.

1. Determine the initial scope and purpose of the Disability Advisory Council.
2. Contract with a facilitator for council development.
3. Recruit members to the council.
 - » As of Aug. 1, 2019, 28 individuals have expressed interest in learning more about being on the council.

A small group of people involved in organizing the Inclusive Emergency Planning workshop is working on these efforts. This will enable the launch of the Disability Advisory Council this fall. This group will meet over two months to work on the following tasks:

- Creating a draft Disability Advisory Council Charter
- Refining what will be asked of the facilitator for the first year
- Developing a work plan
- Exploring funding possibilities
- Developing base requirements for council membership and review the individuals interested
- Setting base expectations for council member involvement (full council and subcommittees)

Contact

Please be in touch with any questions about this workshop summary or the Disability Advisory Council at oregon.masscare@dhsosha.state.or.us.



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