

Good morning, my name is Sarah Launderville and I'm the executive director of the Vermont Center for Independent Living and the President of the Vermont Coalition for Disability Rights. Thank you for the invitation today to testify on H.901.

I appreciate the bill and how it addresses the holes we currently know are in emergency preparedness and response systems in Vermont. We believe that the inclusion of people with lived experience can help make stronger systems.

VCIL is a disability led organization of people with disabilities working together for dignity, independence and civil rights. We were founded in 1979 and we provide supports and programs as well as offer education, technical assistance and systems work to enhance Vermont and break down barriers that people with disabilities are experiencing.

We've been involved in emergency preparedness as well as response for many years in different ways. Unfortunately, in the most recent past, we find ourselves always dealing with emergencies as they happen and working to encourage the system to change, only to find that after the existing emergency the system goes back to one that fits the needs of most, but not people with disabilities.

Our systems are built on ableist models. Ones that favor people who can walk, who have a car and can drive, who can read or see, who can communicate by talking or hearing information, who have a place to live permanently, who have access to cell phones, english speakers, people who understand social media and who take in information in a "neurotypical" ways, or their presentation fits dominate cultural norms.

We set up systems and leave people out for lots of reasons but mostly because of the perception and reality that it costs money or it takes effort to build something stronger. We have buildings with stairs, press conferences with no American sign language interpreters, social media posts with no visual descriptions,

communication that has complicated language, complicated paperwork that needs to be filled out electronically and systems that fail for people when seeking a reasonable accommodation.

Our systems in emergency response are highly dependent on volunteers, towns and people, most who haven't been educated on what the Americans with Disabilities Act requires, or even simple etiquette on how to be around people with disabilities.

And, in some instances have leadership that resent their responsibilities connected to disability altogether and discriminate outwardly to people and families with disabilities. We have school systems not providing the supports to students and schools themselves that leave students with disabilities without equal access that range from participating in field trips to a safe response during drills and actual emergencies.

In recent years, VCIL has found ourselves at the center of conversations and complaints from disabled Vermonters about these systems.

The lived experience and the inclusion of that experience in planning and implementation is something that can help change the system but only if done in a way that doesn't minimize the inclusion of those voices or go back to a different system when the crisis is over. The problem is for years, people with disabilities have been asked to participate in this sort of work, only to be met defensiveness of people being paid to provide the services, or people who dismiss the voices of those who have been oppressed, or upset because the person raising the issue is identifying something they don't understand or will cost money to fix.

When the flooding hit in most recent history, VCIL and other advocates met with FEMA every single day for three months and then tapered to weekly meetings. We worked to ensure that our peers in the community were getting what they needed including medication, and food. We brought issues to the team as the

arose. Our FEMA contact for disability would raise and help address individual issues, and we coordinated the coalition of organizations supporting people with disabilities.

So many volunteers and groups stepped up too. When I remember that time, I remember all the good of people helping, but I also recall what could have been better and the complaints of people that could have been avoided had there been good practice in place, or a stronger understanding of disability.

In one situation a community leader helped bring the community together by holding conversations within the municipality. We and individuals with disabilities asked for ASL interpreters and live-captioning for the zoom portion of the conversation. There wasn't an actual group responsible for the meeting, and that translated into nobody taking responsibility for accommodations of people with disabilities.

We were told that there wasn't enough money. Leadership asked VCIL to pay for the accommodations that under the ADA they were responsible for, but it got better- The city said that the community group was running the meetings, and the community group said it was a coalition of them including the town. Making it one of these "grassroot responses" in which nobody was technically responsible to ensure people with disabilities were included in that conversation in a meaningful way.

Nobody wanted to take that responsibility, and nobody had a budget that would help this group hold the meetings accessibly. That's poor planning. Deaf and Hard of Hearing individuals were actively asking to participate in the conversation and they would have been left out, but in the midst of our central office being completely destroyed by the flood just like many people and moving our employees to home based work- most of whom are disabled themselves and trying to figure out how to keep moving forward VCIL paid for those accommodations.

People were ready to congratulate and give awards and concerts to the able-bodied volunteers who were mucking out the buildings and homes which I'm not trying to diminish because the response was great. But as we raised the issues of inaccessibility, we were met with "come on, we're trying the best we can." And "we're all in this together"... a famous quote from the most recent pandemic that people with disabilities were also left behind in. All upholding a system that didn't really want to hear from people with disabilities and Deaf Vermonters unless it fit into their box not having to pay for it and not having to change the facilitation for "just a few people".

Around that time, we also heard from disabled people experiencing homelessness that there was a noticeable increase in "helpers"—social workers and volunteers who began showing up regularly to check on people's safety and needs. Although well-intentioned, this influx had an unintended impact: some community members chose to move deeper into the woods to create more distance. Many of the helpers lacked the experience, relationships, and understanding needed to respectfully engage with that community, and their presence felt intrusive rather than supportive.

During these emergencies and the pandemic information was not shared in accessible ways. Organizations like Green Mountain Self Advocates made accessible public service announcements in Plain Language and on a regular basis Deaf advocates at the beginning of every emergency continue to remind the media and Governors office to provide ASL interpreters fully on the screen so Deaf Vermonters are getting that information in real time. The fact that this is still not baked into regular practice feels like outright discrimination to me. One tv station asked me after I called to advocate for the interpreter to be shown fully on the screen and said "not to be disrespectful, but how many Deaf people live in Vermont" That's the type of attitudinal and communication barrier that causes people to die during emergencies.

The pandemic has also been a place where so much has changed, but when it benefited more of the general public, the public health emergency was lifted but even when VCIL was advocating for masking, testing and vaccinating because our peers are still at risk, it was met with nothing. Our state actually gave away parts of the stockpile that we were begging for. We have so much information on ways we asked for help from different departments and with met with nothing. In order for these systems to really respond, it needs to include all parts of government because our systems of support to people with disabilities is across different parts of government all with different experience or plans around emergency prep and response.

These examples, and frankly a lot more that we have are symptoms of systemic ableism, where emergency structures were built assuming nondisabled bodies, needs, and communication styles.

In terms of the bill specifically, VCIL is in support of:
The requirement that emergency management systems incorporate disability expertise, include people with lived disability experience, and adopt the C-MIST access and functional needs framework to identify and accommodate disabled people's needs.

These changes are essential and the implementation will only succeed if Vermont addresses the structural issues that repeatedly undermined safety for disabled residents. Having a focus on functional needs and the barriers that are around us for lot of different communities of people, including people with disabilities, culturally Deaf people, people experiencing homelessness, elders, people without transportation access, etc. allows us to have important information to aid in preparation and response to emergencies. In California they developed an [Office of Access and Functional Needs](#).

As we look at the failures of the current system, H.901 has a requirement that emergency plans explicitly address shelter siting, universal access, accessible communication, and diverse functional needs responds directly to these failures.

We really appreciate that H.901 has stayed away from relying on disability disaster registries which tends to put the responsibility on individuals and systems that don't always have safe guards. While some people appreciate having emergency response cards and systems around that, they need to be embedded in a way with people who are very well trained in health record confidentiality and understanding.

VCIL offers skill trainings to individuals who then develop their own emergency response plans and we have received funding from local businesses and the VT State Independent Living council to support emergency kits that people with disability build from their own personal needs, which go beyond a one size fits all emergency kit.

We appreciate the requirement that that municipalities partner with disability-led organizations across all phases of emergency management which moves Vermont toward a more just, equitable model rooted in community power, not paternalism. We recommend that this be compensated. By putting this requirement, we know that municipalities will reach out and ask for names of disabled residents and use their information to build plans. The emotional toll that it takes for individuals to participate in these sorts of working groups can be immense and we have lots of examples of how people with disabilities have been used, and reports are put out but that the "professionals" over-ride that lived experience expertise.

As testified to earlier and in other committees over time, there is a critical missing piece that emergency systems rely too heavily on volunteers.

Vermont's emergency management infrastructure, especially at the municipal level often depends on well-intentioned but untrained or undertrained volunteers. While volunteerism is a proud part of Vermont's identity, this model has repeatedly failed disabled people because:

Volunteers are not often trained in disability rights, the ADA, or inclusive practices.

Many do not understand access and functional needs or communication accessibility

Volunteers may and have unintentionally caused harm by making assumptions about capacity, mobility, communication, or medical needs and breaking confidentiality.

Emergency roles change frequently, meaning knowledge and training are rarely consistent or retained.

And, when volunteers rather than trained professionals or disability-informed staff are responsible for evacuation, shelter operations, communication, or transportation coordination, disabled people face disproportionate harm. This over-reliance on untrained volunteer labor is not sustainable and perpetuates inequity.

H.901's provisions requiring consistent standards in training, accessible communications, shelter operations, and planning create a pathway to correct this. But to succeed, training must extend far beyond paid staff to include the volunteers on whom municipalities rely on every day and without training, systems designed to protect disabled Vermonters will continue to fail them. Training should be led by disabled and Deaf people.

To fulfill H.901's requirement that people with lived disability experience participate in emergency management bodies, Vermont must ensure that participation is accessible, including

remote participation, transportation supports, multiple communication formats, and flexible scheduling.

The participation must be compensated.

Sharing lived experience is expert labor. Stipends are essential to prevent the exploitation of disabled Vermonters whose insights are foundational to implementing H.901 effectively.

In Florida Centers for Independent Living are a contracted partner in mass response work. [See here](#). In VT that would look a little different and would include many Deaf and Disability led organizations.

By providing compensation, Vermont affirms the leadership and value of disabled community members, consistent with the intent of the bill.

In addition, we have strong partnerships with [The Partnership for Inclusive Design Strategies](#), led by disabled people who are experts in disaster prep and response and I'd encourage the committee to ask them to provide testimony on this bill. We've been involved in supporting two important federal pieces of legislation that the committee might find helpful and linked here: [The Real Emergency Access for Aging and Disability Inclusion for Disaster Act \(READDI\)](#) and [Disaster Relief Medicaid Act \(DRMA\)](#). We've held town halls in the past and gathered content that also might be helpful to the committee.

There is so much to unpack and I've tried to give you as much details but have so many more experiences we could share. Overall we are very supportive of a bill that centers people with disabilities, their experiences and moves to address inequities that for far too long have caused harm to disabled individuals living in Vermont.

Respectfully submitted,
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