

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

Testimony on LB 1104

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Nebraska Legislature
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Good afternoon Senator Brewer and members of the Committee. For the record my name is Brad B-R-A-D Meurrens M-E-U-R-R-E-N-S and I am the Public Policy Director at Disability Rights Nebraska. We are the designated Protection and Advocacy organization for people with disabilities in Nebraska. I am here in strong support of LB 1104.

I do want to make one point explicitly clear and up front. I do not read this bill as adversarial or hostile to NEMA. We asked NEMA to participate in a disability preparedness [webinar](#) about disaster/emergency planning last fall and they graciously agreed to participate. We have greatly appreciated NEMA's pushing out the announcements for (and participating in) the Niagara University emergency preparedness trainings held this past fall across the state. We were pleased to see that NEMA posted substantial and quality content during Emergency Preparedness Month last October. I am not casting aspersions today; rather I see this bill as a call for broader public awareness as well as increased inclusion and collaboration among emergency planners and people with disabilities.

People with disabilities in Nebraska comprise around 10% of our state's population¹ and there are Nebraskans with disabilities in every county². These are our family, friends, neighbors—our community; they have the right to be rescued during disasters like anyone else. However, as Senator Day's introduction, the National Council on Disabilities (NCD) series of reports³, and our own report "2nd Class During the Pandemic" indicate⁴, sometimes despite the best intentions and "optimal" planning by

¹ Erickson, W., Lee, C., von Schrader, S. (2022). *Disability Statistics from the American Community Survey (ACS)*. Ithaca, NY: Cornell University Yang-Tan Institute (YTI). Retrieved from Cornell University Disability Statistics website: www.disabilitystatistics.org

² Paul, S., Rafal, M., & Houtenville, A. (2020). *2019 State Report for Nebraska County-Level Data: Prevalence*. Durham, NH: University of New Hampshire, Institute on Disability. See <https://disabilitycompendium.org/>

³ National Council on Disability reports, see:
[Saving Lives: Including People with Disabilities in Emergency Planning](#) (2005)
[Emergency Management and People with Disabilities: Before, During, and After](#) (2005)
[People with Disabilities and Emergency Management](#) (2008)

⁴ See "2nd Class" report at page 8: "TestNebraska's service was inaccessible the day it was unveiled in May 2020 and just as inaccessible when it folded in July 2021. We do give credit that, per state law, *TestNebraska's website was*

emergency managers, people with disabilities (and those with functional needs) and their unique circumstances/needs can be overlooked. People get “left behind” during crisis. Given that the majority of Nebraskans do not live with a disability, disability issues, needs, and barriers are not fully addressed or can get missed.

We see this bill as having three parts: Part I adds definitions of “disability” and “functional need”. Relatedly, Part II adds “disability” to the title of the existing functional needs registries. The change in the title we think adds clarity and ensures that people with disabilities know they are included, too. Hence, the definitions mentioned above. Part III is the main thrust of the legislation: it simply requires that NEMA, when developing and revising their Emergency Operations Plans, seek the advice and assistance of disability organizations and providers, as well as to maintain a list of organizations (not just people) who have expertise or knowledge regarding disasters. We note that NEMA is already required to consult with governmental agencies and the “private sector” in this process, so we are puzzled that disability organizations or the disability community are not. Hence LB 1104’s impetus.

While we are very pleased to see that “disability” and “functional needs” occurs 36 times in the 2020 Template for County/Local Emergency Operations Plans, I would point out that this inclusion does not benefit from any direct consultation with disability groups or individuals. Rather the inclusion of disability/functional needs and addressing those specific needs, seems directed by emergency managers or designees themselves, what they think should happen. As all the NCD reports show, and especially the 2019 NCD report regarding institutionalization, decisions made in this fashion can backfire.

- In 2017, during Hurricane Harvey, the National Council on Independent Living reported “a disturbing trend of persons with disabilities who had lived in the community [who] were transferred to institutional settings, either due to lack of post-shelter housing options or because of the difficulties of navigating disaster recovery.”⁵
- Although there are numerous factors that lead to institutionalization during and after disasters, all are rooted in the medical model of disability; poor planning; and ***lack of understanding of civil rights laws that protect people with disabilities during and after disasters.***⁶
- Emergency responders, managers, and even some members of the disability community consistently demonstrated a lack of understanding that federally-funded disaster-related programs and services must be accessible under the Rehabilitation Act and that these rights cannot be waived. They also lacked an appreciation for the rights that people with disabilities have under the ADA to equal access to disaster-related programs and services and to receive services in the most integrated setting appropriate to their needs. It appeared that many saw the practice of institutionalization and the denial of equal access to disaster-related programs and services that could lead to institutionalization as acceptable occurrences. Many either did not appreciate or did not articulate that these practices are unlawful. It also appeared that many did

screen reader-friendly for people who are blind and visually impaired. However, since the program required individuals to drive, it was otherwise inaccessible.

⁵ National Council on Disability, (2019) “Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters”, https://ncd.gov/sites/default/files/NCD_Preserving_Our_Freedom_508.pdf

⁶ Ibid, page 39.

not appreciate how closely the lack of equal access to disaster-related programs and services was linked to institutionalization. And, even among highly knowledgeable community leaders, the option of institutionalization seemed an acceptable solution considering the circumstances eschewing planning as an issue to be dealt with after the disaster.⁷

I would also point you to the “25 Commandments for Disability Inclusion” handout. In particular, commandments:

6. Thou shalt not confuse government leadership and public safety obligations to support community inclusion with being led by the people you serve. The role of government is to support community leadership, not to serve in the role of leader. Nothing about us without us. Plan with us, not for us.

11. Thou shalt ALWAYS provide equal access and meet non-discrimination requirements before, during and after disasters. These are legal civil rights obligations. There are no waivers or loopholes to these obligations in a disaster.

12. ...Partner with the community programs who are most knowledgeable about the needs of the people who live there. Paratransit, independent living centers, developmental and mental health service providers, meals on wheels, home health and aging services, special education and dialysis centers are great examples. Help them to find the resources to help your community achieve realistic whole community inclusive planning and response strategies.

5. Thou shalt not speak with the public about emergency and disaster related issues, provide emergency alerts, warning, actionable information, print or electronic information or programs and services without providing equal, timely and effective communication access via qualified sign language interpreters, real-time open captioning, large print, plain language, braille, and instructions for obtaining effective communication accommodations. Information must be accessible to be actionable.

23. Thou shalt never assume that addressing physical access is enough to meet the access and functional needs of the people in your community. Be sure to engage experts with lived experience with mental health, aging, sensory and communication disabilities, chemical and environmental sensitivities, autism spectrum, intellectual and cognitive disabilities and chronic health conditions throughout planning and preparedness as well as recovery and mitigation.

The people who know best about disability issues and how to plan/address them are those who have lived experience with disabilities and those who are engaged in disability advocacy/services delivery. Disability organizations can help tremendously in this area. NCD reports in 2005⁸:

- “I wish we’d had a stronger relationship with all the other community-based agencies so we could coordinate efforts,” CIDNY’s executive director said. **“The time to build relationships is not**

⁷ Ibid, page 40.

⁸ National Council on Disability (2005) “Saving Lives: Including People with Disabilities in Emergency Planning”, https://ncd.gov/sites/default/files/Documents/saving_lives.pdf

in the middle of a crisis. I wish we'd paid more attention to efforts to include people with disabilities in disaster planning. I wish we'd had better mechanisms in place to get the word out that we exist and what we can do for people who need help" (ILRU 2002a)."

- People with disabilities should not assume that emergency and relief agencies understand accessibility, accommodations, communication, transportation issues, or any other aspect of disability or independent living. If people with disabilities haven't worked to raise the awareness of emergency personnel before the emergency, people can plan to spend a lot of time educating them in the midst of the crisis (ILRU 2002c). In the past, CIDNY had been invited to participate in various emergency preparedness meetings; but in the day-to-day reality of providing independent living services after 9/11, those meetings were not given much priority. That has changed now, and CIDNY hopes to build on the relationships and learning that have occurred since 9/11.

Looking at the Emergency Operations Plan template⁹, there seem to be many areas where disability organizations/individuals can help:

- Title page: The word "handicap" is antiquated and pejorative.
- Page E-15 lists one non-governmental organization to provide advice to the public.
 - *Why not include disability organizations, too?*
- Page G-4: "The local/regional Public Health agency(ies) will work in partnership with the Emergency Manager and the mass care shelter manager **to plan for and assist them to accommodate people who have access and functional needs. Public Health will provide recommendations for communications methods, public information message development, special equipment and supplies that may be needed and locating local care providers to assist individuals whose needs cannot be met at the shelter.**"
 - *This seems to be a "plan for, not with" situation*
- Page I-3 is reserved to list county organizations/resources for functional need resources.
- Page A-54: "Warnings procedures and protocols have been developed and will be implemented for identified access and functional needs populations."
 - *Are these accessible? Again, "plan for not with"*

And to stick the dismount (it's Olympic season) see page 48 of the NCD report "Saving Lives":

"It is critical for emergency preparedness and response plans to address and accommodate all individuals, including vulnerable populations. Numerous agencies and organizations exist that have extensive knowledge and expertise on the needs of these populations. CBOs [Community-Based Organizations] are often a part of naturally occurring local networks, which are powerful support tools (Davis and Cahill 2003). CBOs have unique and credible connections with—and expertise in delivering services to—people with disabilities and activity limitations. This unique know-how and understanding can be a valuable resource during planning, preparedness,

⁹ See <https://nema.nebraska.gov/sites/nema.nebraska.gov/files/doc/standard-leop.pdf>

response, recovery, and mitigation activities. CBOs should be included as partners in working with local, state, regional, and federal public and private response agencies to deal more effectively with and understand the needs, geography, demographics, and resources of their local areas. “

That concludes my testimony. I would be happy to answer any questions.