

SECOND CLASS DURING THE PANDEMIC

How Nebraska Discriminated Against People with Disabilities

Introduction

People with disabilities have been disproportionately impacted by the COVID-19 pandemic because the virus is more likely to be lethal for those with an underlying medical condition, those who are elderly, people with serious mental health diagnoses and those with intellectual and developmental disabilities. Not only are people with disabilities more susceptible to contracting the virus, often with fatal consequences, but being forced to live in close proximity with other people also makes transmission more likely so that people with disabilities who live in congregate facilities such as group homes, long-term care and assisted living facilities, state-operated institutions, prisons and jails have been even more vulnerable during the pandemic. According to the latest census data, approximately 12% of Nebraskans are people with a disability and there are people with disabilities in every single county across the state.¹

As we documented in our November 2020 report “A Widening Divide: How Nebraska’s Pandemic Response Has Left Behind Many People with Disabilities,”² the state’s pre-pandemic planning unfortunately overlooked care for people with disabilities. Now, as we approach the two-year anniversary of the virus’ appearance, we have identified a number of legislative solutions to ensure the protection of all Nebraskans in the event of any future emergency or pandemic.

THE WORK OF DISABILITY RIGHTS NEBRASKA

Disability Rights Nebraska is the designated protection and advocacy system for the State of Nebraska. As part of our federal mandate, Disability Rights Nebraska monitors institutional facilities, investigates allegations of abuse and neglect, pursues administrative, legal and other appropriate remedies, and provides information, referrals and training. Monitoring the conditions where people with disabilities work, live and receive supports and services is one of the most important functions of our organization. Through the monitoring process, we are able to ensure the rights and safety of residents in congregate facilities, discover incidents of abuse, neglect and exploitation; raise

knowledge about the work of Disability Rights Nebraska, and provide education to individuals with disabilities about their rights.

Since the pandemic began, we have done remote monitoring to ensure the safety of residents of congregate facilities. We have interviewed staff and residents of over 100 different facilities, including homeless shelters, county jails, day programs and group homes for adults with developmental disabilities, day programs and assisted living facilities (ALFs) for adults with mental illness, long-term care facilities also known as nursing homes, and juvenile detention facilities.

We have also collaborated with a coalition of other nonprofits and agencies stretching across the state to identify the unmet pandemic needs of Nebraskans with disabilities. From the earliest days of uncertainty to the much-anticipated rollout of vaccines to the present time, we have repeatedly witnessed the same tragic story: every aspect of the state's pandemic response has left behind Nebraskans with disabilities despite the fact they are most at risk from the virus. In this report, we will outline the three most crucial gaps in the state's pandemic response: the COVID-19 testing program, the crisis standards to address hospital shortages, and vaccine access.

Three Deadly Gaps in Nebraska's Pandemic Response

TESTNEBRASKA

TestNebraska was launched May 4, 2020. The program required two steps: (1) the individual was required to register online and (2) the individual was required to drive to a testing site. The program obviously posed significant barriers for people with disabilities. People without any internet access, people without the ability to navigate the registration website, people who didn't have a car, people who had no access to transportation to a testing site, and people who were unable to sit in their vehicle for long periods due to their disability were all simply left out.

Despite repeated written requests by Disability Rights Nebraska for accommodations such as a phone registration option and an in-home testing program, the state failed to make any changes to TestNebraska. As a result, Disability Rights Nebraska filed a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights in June 2020 on behalf of ten advocacy organizations who represent Nebraskans with disabilities.³ The federal investigation by the Office for Civil Rights ("OCR") is pending as of the time of this report.

Even after the formal OCR complaint was filed, the state of Nebraska entered into additional contracts with Nomi Health to manage and expand TestNebraska. A careful review of all contracts available through the state contract database reveal that Nebraska paid nearly \$44 million⁴ to Nomi Health and never included a provision for the testing program to remedy the ADA violations.

The state disbanded the still-inaccessible TestNebraska in July 2021. Ten days later, in

response to the steep increase of Delta variant cases, the same private that company contracted for TestNebraska opened a limited number of drive-through testing sites.⁵ At the time of this report, there appear to only be Nomi testing sites available in Scottsbluff, Grand Island, Omaha and Lincoln.⁶ Even at the height of the increased hospitalizations and deaths from the Delta variant, the state made no effort to expand COVID-19 testing, and the testing programs remain inaccessible to people with disabilities.

Nebraska's testing program has been discrimination, plain and simple. But it did not just leave behind people with disabilities—the state's inadequate response created “testing deserts” for people in greater Nebraska, as well. Private testing companies have begun collaborating with public health departments to expand testing capacity in rural Nebraska, but testing availability in the parts of the state with the lowest vaccination rates remain a concern as a long wait for a test means further exposure to other people.⁷ One journalist described a three-hour drive to be tested, since her community simply does not have chain pharmacies such as Walgreens or CVS to supplement the public testing programs: “In rural Nebraska, a participant must spend hours on the phone negotiating a test. They may have to drive long distances, and even though rapid testing may be available, it's a gamble whether health centers have tests available. The participant may have to wait for days, losing hours and money, often to receive a negative test three to five days later. It's costly, and it requires time and energy many people do not have.”⁸

The pandemic is not over, and the need for free accessible COVID testing is not over. In order to come fully out of this pandemic—and in order to be prepared for a future emergency—state officials must acknowledge the deadly gaps they've left and work to close them.

CRISIS STANDARDS OF CARE

Crisis standards of care are the rules that come into effect in the event of medical shortages, whether that be hospital beds, ventilators, prescriptions, or other life-saving care. When resources are scarce, doctors have to decide who will receive care and who will not. Many states have established standards in statute or regulation to guide the doctors' decisions, but Nebraska has no such standards.

In the pre-vaccine period of the COVID-19 pandemic, some states proposed blatantly discriminatory policies that would put people with disabilities at the back of the line for care. For example, people with disabilities in New York were confronted with the possibility that their daily use personal ventilators could be removed from them and re-allocated to those deemed more in need.⁹ Oregon hospitals had several shocking incidents where people with intellectual or developmental disabilities were refused care simply because the hospitals were prioritizing patients without disabilities.¹⁰

Disability Rights Nebraska reached out to Governor Ricketts and state health department officials in March 2020 in response to these scandals in other states and requested the creation of

clear, ethical, medically appropriate standards. We provided nationally endorsed standards of care as examples¹¹ and requested the opportunity to have people with disabilities at the planning table in the development of crisis standards. No Nebraska officials responded. For months, advocates for Nebraskans with disabilities pressed for information on the development of crisis standards—only to learn in November 2020 that the state had abdicated any responsibility and left the creation of standards to a panel of private hospitals. The resulting document was not made publicly available until May 2021 and has no binding legal status even among the hospitals that created it. It is also unclear whether the document was sent to health care providers outside the few entities that created it.¹²

Other states have already endured the impact of choosing who receives care in an overextended medical system, and the tragic news stories range from a veteran in Houston who died from gallstones because the ICU beds were full to the Alaskan patient taken off dialysis and left to die because there were not enough nurses to staff the dialysis machine.¹³ As of the writing of this report, Alaska and Idaho both had to invoke their crisis standards of care in the fall of 2021 due to their overwhelmed hospitals. One hospital director spoke about the immediate impact of those standards: an older woman who'd had a stroke was treated and released that same day instead of being held overnight for observation. The patient was the hospital director's own mother. Given the need to triage limited staff, beds, and machinery, she was required to send her own mother home.¹⁴

Tragic stories of people devalued by hospitals due to their disability became all too common during the pandemic. Michael Hickson was a Texan living with quadriplegia following a heart attack on his way to work at the age of 43. His wife and five teenage children were talking to him regularly in person and on the phone while he was hospitalized with COVID-19 in June 2020. His family knew the virus was especially threatening for Michael due to his underlying disability, but he was alert and responsive, making it particularly hard to understand why the hospital decided to end care for him and move him out of the ICU into hospice. When Ms. Hickson confronted his doctor about the decision,

DOCTOR: “As of right now, his quality of life — he doesn't have much of one.”

MS. HICKSON: “What do you mean? Because he's paralyzed with a brain injury, he doesn't have quality of life?”

DOCTOR: “Correct.¹⁵”

Nebraskans must have clear, binding, ethical guidelines in state law to prevent any health care rationing decisions being made in a discriminatory manner.

VACCINE ACCESS

A new report published by the CDC found that adults with disabilities have little vaccine hesitancy—but were much less likely to actually be vaccinated due to the difficulties in obtaining the

vaccine.¹⁶ In other words, if Nebraska can remove barriers, our most vulnerable friends and family will be able to be vaccinated. Vaccine access has presented several different concerns for Nebraskans with disabilities: (a) the lack of prioritization for people with disabilities, (b) shift of vaccines to the local health departments without guidance or advance planning, (c) lack of in-home vaccinations, and (d) requirements for unvaccinated staff working with vulnerable populations.

Vaccine prioritization. Initially, with vaccines on the horizon, the state published a written vaccination plan in late 2020. The written plan outlined prioritization for how limited vaccine doses would be made available. The plan appropriately included people in vulnerable groups—the aged, people with disabilities and qualifying medical conditions, people in congregate facilities where risk of transmission was high—as a very early priority category. The original plan (which has since been removed from the Nebraska DHHS website) met the best practices and criteria recommended by medical experts and the Centers for Disease Control.

Once vaccines arrived, the state began implementing the written plan to deliver doses to the first tier of recipients. As frontline health care workers and the elderly were vaccinated, the Governor announced he was abandoning the existing plan and announcing an age-driven eligibility instead.¹⁷ While people who are senior citizens were appropriately prioritized due to their higher rates of susceptibility, the state’s age-based plan put Nebraskans with disabilities at risk since it was not based on medical criteria. For example, a 20-year-old with Down Syndrome is known to be at much higher risk from COVID-19¹⁸, but her healthy 50-year-old mother would receive the vaccine months ahead of her. No explanation was given for the Governor’s decision to set aside the CDC-recommended plan that had been developed by state medical officials.

Vaccines shifted to local health departments. At the same time as the state’s shift to an age-based standard was announced, the state further announced all distribution would be done by local public health departments with no state involvement or oversight. Interviews with local public health directors by Disability Rights Nebraska staff revealed their surprise at this development. “We had no advance warning,” one director told us. “If the state intended to have us be the primary vehicle, you’d think they would have included us in the planning—well, if there was a plan.” The state instructed local health departments to hold back 10% of their available doses for people with disabilities—but unlike the original written plan, offered no definition of which disabilities would qualify. The state did not provide guidance or aid to the local departments to explain that vaccine clinics must be held in accessible ADA-appropriate facilities, for example, leading to a few notable errors early on.

Without state guidance, the local health departments were left in a vacuum. Disability Rights Nebraska moved to fill the vacuum and provided CDC resources to every local health department director to offer guidance on ADA accessibility concerns for in-person clinics and how to identify the priority category of people with disabilities.

In-home vaccination options. With the vaccination rollout shifted entirely to the local health departments without notice, the local entities were forced to implement the vaccine program quickly. In the early months, vaccine demand outstripped supply, which significantly strained the local departments. As months passed, it became clear that vaccination clinics posed the same barrier as TestNebraska: the program required participants to be mobile and able to leave their homes for the vaccine. The state had never crafted an in-home testing program or instructed local officials how to address the needs of Nebraskans who were medically fragile, living in a congregate facility, or simply without the money and ability to travel to a clinic. For several months, Disability Rights Nebraska requested that state health officials create an in-home option for people with disabilities and provided successful examples of such programs implemented in other states.

Disappointingly, the state failed to respond, though local health departments began to create programs as vaccination rates rose. Over the summer of 2021, Disability Rights Nebraska reached out to every local health department to determine whether they would provide in-home vaccinations and whether the option was clearly advertised. In August 2021, a survey by Disability Rights Nebraska revealed nearly every local public health department had a program in place to provide a vaccine for someone with a disability if they requested it. A few small departments in greater Nebraska without an in-home option agreed to review their capacity for in-home vaccinations after contact from our agency. The efforts of local public health departments to ensure that vaccines were accessible for vulnerable and at-risk communities is a model of planning for state officials to learn from.

Unvaccinated staff working with vulnerable populations. Nebraskans living in congregate facilities such as the Beatrice State Development Center, the two Regional Centers, prisons, jails, juvenile facilities, assisted living facilities, group homes and nursing homes have contact with various staff throughout their day. The residents of these facilities have no choice: they receive the basics of life such as food and medication from the hands of these employees. While the residents of congregate facilities were early recipients of vaccines, there has been no mandate requiring vaccination of staff.

Not all congregate facility staff vaccination data is collected by the state, though staff in long-term care facilities (also known as “nursing homes”) must report their vaccination data to the federal government. As of the date of this report, approximately one-third of nursing home staff caring for vulnerable aged Nebraskans are unvaccinated: statewide only 64% of health care personnel were vaccinated.¹⁹

In the absence of mandated reporting from other congregate facilities, in October 2021, Disability Rights Nebraska began making survey calls to group homes where adults with disabilities reside. The results show some positive news—for the most part, residents of these homes are between 90-100% vaccinated. We were very concerned to learn that staff vaccination rates lag far behind, though: only 45-75% of staff are vaccinated. We have surveyed only one congregate facility with 100%

staff vaccination. State facility administrators have reported similar data to our investigators: staff at the two regional centers and at the Beatrice State Developmental Center are not all vaccinated despite their daily contact with vulnerable residents.

Assuming that there may be similar staff vaccination rates in the prisons, juvenile detention centers, and other congregate facilities, we are concerned whether there are adequate measures in place to ensure the staff having direct contact with residents do not bring COVID-19 to their workplace.

In the absence of state vaccine mandates, it is very concerning that Governor Ricketts actively sought to recruit unvaccinated nurses to work with vulnerable populations in congregate living facilities. Such effort places health care workers known to pose a risk due to their unvaccinated status into contact with those living in our state-run veterans' homes, youth detention facilities, psychiatric hospitals and prisons—all places where the residents cannot socially distance from each other.²⁰ Medical associations unanimously support vaccine mandates for health care workers, including the American Hospital Association, the American Medical Association, the American Nurses Association, the American College of Physicians, the American Academy of Pediatrics, the National Association for Home Care and Hospice, and more. The Governor's move may not affect some entities, since the U.S. Department of Veterans Affairs has a vaccine mandate²¹ along with a joint resolution by the largest health care systems in Nebraska, including Madonna Rehabilitation Hospitals, Bryan Health, Methodist, CHI Health, Nebraska Medicine, and others.²²

Legislative Steps to Protect Nebraskans in the Next Pandemic or Disaster

Based on Disability Rights Nebraska's investigation, there are several clear steps that must be taken in statute or regulation to protect Nebraskans with disabilities from the failures this pandemic revealed.

INCLUSION OF PEOPLE WITH DISABILITIES IN PLANNING

While Nebraska may have been surprised by the virulence of COVID-19 and unable to initially include people with disabilities at the table, enough time has passed to allow thoughtful planning with advocates at the table. Nebraska's Emergency Management Act currently seeks to "Reduce the vulnerability of people and communities of this state to damage, injury, and loss of life and property resulting from natural, technological, or manmade disasters and emergencies..."²³ primarily by charging the Adjutant General with creating an emergency operations plan²⁴ but has no explicit requirement that the public entities include planning for the needs of Nebraskans with disabilities.²⁵ Sister states have created disaster planning advisory committees charged with the duty of reviewing Emergency Management plans and offering recommendations from the perspective of

serving people with disabilities. See, for example, the law recently passed in Illinois.²⁶

ASSURANCE THAT STATE PROGRAMS WILL BE ACCESSIBLE

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,²⁷ TestNebraska’s website was screen reader-friendly for people who are blind and visually impaired. However, since the program required individuals to drive, it was otherwise inaccessible. We urge passage of legislation that requires the state contracts with private entities such as Nomi Health for TestNebraska to include accessible services and require such contracts for a clause relating to ADA accessibility by the state department signing such contract. This could include an expansion of current state law requiring technology access to be more broadly accessible. Remedial legislation could also mandate ADA review of all contracts--the Department of Administrative Services is currently charged with review of public expenditures to ensure “the appropriations are being judiciously and economically expended”²⁸; this or another appropriate agency ensuring contracts guarantee accessible services will protect the state from entering into future contracts that fail to provide service to all Nebraskans.²⁹

CRISIS STANDARDS OF CARE

Multiple statutory models exist for crisis standards of care. The privately created document constructed during the pandemic provides an excellent starting point, but Nebraska needs public, clear, and enforceable standards set forth in law rather than a “handshake agreement” in questions of life and death.

Conclusion

Nebraskans with disabilities have faced and overcome immense obstacles since the beginning of the pandemic. Frustratingly, the state’s pandemic response has left these vulnerable populations behind since the beginning. We hope that legislative action will be taken to ensure equitable access to life saving programs and services for the future.

Endnotes

- 1 <https://disabilitycompendium.org/>
- 2 <https://www.disabilityrightsnebraska.org/resources/covid-19-updates/a-widening-divide.html>
- 3 <https://www.disabilityrightsnebraska.org/resources/covid-19-updates/covid-19-equal-access-to-healthcare.html>
- 4 According to the Nebraska Department of Administrative Services contract database, from April 2020 through July 2021, Nomi Health was paid \$43,958,346.49. <https://statecontracts.nebraska.gov/>
- 5 Bayley Bischof, “NOMI Health testing sites expanding across Nebraska, providing free COVID-19 tests,” KOLN/KGIN. (9-16-21) <https://www.1011now.com/2021/09/17/nomi-health-testing-sites-expanding-across-nebraska-providing-free-covid-19-tests/>
- 6 https://testing.nomihealth.com/easy_registration/139/onsite
- 7 Julie Anderson, “Health departments, companies work to fill COVID testing gaps in rural Nebraska,” Lincoln Journal Star (10-11-21) https://journalstar.com/lifestyles/health-med-fit/health-departments-companies-work-to-fill-covid-testing-gaps-in-rural-nebraska/article_fb033736-6fe8-5061-8880-f10c95a6ce01.html
- 8 Emma Krab, “Why the Nebraska COVID-19 testing resource gap needs to be closed,” Daily Nebraskan. (9-13-21) http://www.dailynebraskan.com/opinion/column-why-the-nebraska-covid-19-testing-resource-gap-needs-to-be-closed/article_557d6c56-141d-11ec-9a1c-7fd17acbb24e.html
- 9 Ne’eman A., “I will not apologize for my needs.” The New York Times. (3-23-20) <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html>
- 10 Joseph Shapiro, “Oregon Hospitals Didn’t Have Shortages. So Why Were Disabled People Denied Care?” National Public Radio (12-21-20) <https://www.npr.org/2020/12/21/946292119/oregon-hospitals-didnt-have-shortages-so-why-were-disabled-people-denied-care>
- 11 See, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr> See also Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020. <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>
- 12 https://www.unmc.edu/healthsecurity/_documents/NE-Crisis-Protocol.pdf
- 13 William A. Haseltine, “America’s New Triage: Covid Crisis Standards of Care,” Forbes. (10-6-21) <https://www.forbes.com/sites/williamhaseltine/2021/10/06/the-crisis-around-crisis-standards-of-care/?sh=73bb9a5b2fda>
- 14 David Mack, “An Unprecedented Event in Modern Medicine: What Happens When a State Fails to Flatten the COVID Curve,” BuzzFeed News. (9-22-21) <https://www.buzzfeednews.com/article/davidmack/idaho-covid-crisis-standards-care>

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- 15 Joseph Shapiro, “One Man’s COVID-19 Death Raises the Worst Fears of Many People With Disabilities,” National Public Radio (7-31-20) <https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities>
 - 16 National Immunization Survey Adult COVID Module, “Disparities in COVID-19 Vaccination Status, Intent, and Perceived Access for Noninstitutionalized Adults, by Disability Status.” (11-1-21) https://www.cdc.gov/mmwr/volumes/70/wr/mm7039a2.htm?s_cid=mm7039a2_w
 - 17 The original vaccination priority plan has been removed from the state DHHS website and replaced with the age-based plan, though it was hastily revised and still as of today is offered as a “draft.” <https://dhhs.ne.gov/Documents/COVID-19-Vaccination-Plan.pdf>
 - 18 Gleason, Jonathan et al. “The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States.” NEJM Medical Society, (March 2021). <https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051>
 - 19 <https://data.cms.gov/covid-19/covid-19-nursing-home-data>
 - 20 Andrew Ozaki, “Ads touting no vaccine mandate for state nursing jobs concerns health organizations,” KETV (8-24-21) <https://www.ketv.com/article/state-draws-backlash-after-advertising-nursing-jobs-with-no-mandated-covid-19-vaccination/37389776#>
 - 21 <https://www.va.gov/opa/pressrel/pressrelease.cfm?id=5703>
 - 22 Kevin Westhues et al, “Nebraska health care systems to require COVID-19 vaccinations,” WOWT (8-12-21) <https://www.wowt.com/2021/08/12/nebraska-health-care-systems-require-covid-19-vaccinations/>
 - 23 Neb. Rev. Stat. 81-829.37(1)
 - 24 Neb. Rev. Stat. 81-829.41(2)
 - 25 Neb. Rev. Stat. 81-829.36 et seq.
 - 26 20 Ill. Comp. Stat. Ann. 3305/23 (West 2021), available online: <https://www.ilga.gov/legislation/publicacts/102/102-0361.htm>
 - 27 Neb. Rev. Stat. 73-205
 - 28 Neb. Rev. Stat. 81-129
 - 29 Modification could be to statute or the Department of Administrative Services Rules and Regulations Concerning the Approval of Contracts for Personal Services found at Title 12 Chapter 1. <https://das.nebraska.gov/director/docs/pdf/Director-Title12PersonalServicesRulesRegs.pdf>

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