

A Widening Divide

How Nebraska's Pandemic Response Has Left Behind Many People With Disabilities

Introduction

People with disabilities are disproportionately at high risk of contracting COVID-19, particularly those living in congregate residential programs, state-operated institutions, prisons and jails, and long-term care facilities. While the impacts of COVID-19 have been felt by all Nebraskans, the pandemic has widened the divide of inequality and left behind large numbers of people, especially those with disabilities. The nature of COVID-19 has a disproportionately lethal impact on those with underlying health conditions¹, the elderly², and people with intellectual or developmental disabilities³: these are the same people who are most likely to be gathered in congregate facilities.

Concerningly, even within those congregate facilities, state⁴ and national⁵ data shows another disproportionate impact upon people of color who are at an increased risk for contracting the virus, for hospitalizations, and for death. Nationwide the racial disparities have been very clear, but unfortunately about 20% of reported positive COVID-19 cases in Nebraska have no race data so it is difficult to assess the

full impact the pandemic has had among communities of color. Even with incomplete data, we know the virus has been particularly deadly among Hispanic/Latino Nebraskans, who make up 11% of the state population but 23% of total hospitalizations for COVID-19⁶.

Since March 2020, Disability Rights Nebraska has been working tirelessly to investigate conditions for people with disabilities through our federal legal monitoring authority. We have prepared this report to lift up the areas of concern that could arise in a future emergency and to call for action on the current unmet needs still impacting Nebraskans with disabilities.

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Monitoring by Disability Rights Nebraska

Disability Rights Nebraska⁷ 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, referral, 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, discover incidents of abuse, neglect, exploitation; raise knowledge about the work of Disability Rights Nebraska, and provide education to individuals with disabilities about their rights.

Pandemic Monitoring Work

Since the pandemic began, Disability Rights Nebraska's monitoring work had to change significantly to ensure that the safety and health of those living in congregate facilities was not jeopardized by outside visitors. Disability Rights Nebraska staff quickly pivoted to implementing a remote monitoring plan. While there have been limitations on some of our client interaction, the remote monitoring actually allowed for a vastly expanded range of residential places.

For example, in addition to continuing our monitoring of congregate facilities such as the Lincoln Regional Center, staff have also conducted remote surveys of almost 100 different congregate facilities that included 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, and long term care facilities also known as nursing homes.

With each survey, we contacted the administration to request a phone interview about how the pandemic was affecting their staff and the people they served. The survey questions covered COVID-19 impact on staffing levels, screening and testing of staff, screening and testing of residents, how social distancing was impacting residents' daily lives, adequacy of personal protective equipment (PPE), and unmet needs. The surveying staff discovered many facilities were transparent and eager to share information. Only a small number of survey targets refused to provide information.

Why the Pandemic Has Been Particularly Devastating for People with Disabilities

Multiple social, economic and health issues place people with disabilities at a higher risk of COVID-19 infection. Consequently, COVID-19 infections in congregate living facilities both break out more rapidly and spread more rapidly among a population that may already have underlying health conditions that make them more vulnerable to acquiring the most serious symptoms. For example, people with intellectual/developmental disabilities are also those most likely to die from a Coronavirus infection: researchers estimate that adults with Down Syndrome are at almost 5 times the risk for hospitalization due to COVID-19 and 10 times the risk for death related to COVID-19⁸. Similarly, elderly people living in nursing homes account for a significant portion of COVID-19 deaths nationwide with approximately one-third of the US deaths being linked to nursing homes⁹. The number is sadly greater in Nebraska: the [Omaha World Herald has reported](#) that data compiled through September 6, 2020 shows that nearly half of Nebraska's total COVID-19 deaths were from nursing homes.¹⁰

The deeply concerning impact on people with disabilities underscored the critical need to focus our monitoring attention on the congregate living facilities across Nebraska with remote surveys.

Early Pandemic Needs Identified by Surveys

From February to the writing of this report, the unmet needs in residential facilities changed significantly. Early on, agencies faced alarming and fundamental gaps in basics such as access to adequate food and personal protective equipment (PPE).

I didn't get any assistance locating PPE until we'd actually had our first COVID-19 death, and then all of a sudden we were a priority. If they'd gotten us supplies earlier, maybe we could have avoided any tragedy.

Food

Particularly in greater Nebraska, we heard some group homes could not purchase enough milk or bread due to local grocery store limits on how much an individual customer could buy—without any guidance from state or county officials, these stores had not made exemptions to their policies for group homes with multiple residents. One group home administrator noted ruefully that if she'd had documentation to educate the store managers, she might have been able to overcome the barriers, but she was left simply traveling far distances to multiple stores to try to ensure her residents had enough food.

Personal Protective Equipment (PPE)

While the whole nation was faced with PPE shortages, many of the facilities we spoke to were particularly distressed that they were not prioritized for receiving supplies. One nursing home director expressed frustration that hospitals got top priority when “We literally have the most vulnerable elderly people with the highest medical needs under our roof, too. I didn't get any assistance locating PPE until we'd actually had our first COVID-19 death, and then all of a sudden we were a priority. If they'd gotten us supplies earlier, maybe we could have avoided any tragedy.” The PPE particularly sought after were masks and hand sanitizer.

Staffing

Many agencies were strained early on by staffing needs. This was acute across the country: the [Kaiser Foundation reports](#) 1 in 3 nursing homes nationwide was reporting a staffing shortage as of June 2020¹¹. Some facilities were already close to the staffing ratios appropriate for their level of care, so having even a single employee home in quarantine could be significant. A few facilities actually moved their staff into the building to shelter in place for a period of weeks to ensure they could provide for everyone in their care. Many of the survey targets—particularly in greater Nebraska—expressed frustration at how long it took for a relaxing of licensure requirements to allow for the hiring of new employees. Some wished that state or county officials could have helped with staffing by loaning National Guard staff to strained facilities or by acting as a network between job seekers and the embattled residential facilities.

Lack of Information from the State

The pandemic has been an ever-evolving landscape with changes in recommendations for preventing transmission, new sources for PPE, and amended regulatory structures. We noted that the Division of Developmental Disabilities had excellent communication with agencies serving Nebraskans with intellectual disabilities; there were weekly calls to provide the latest information and well organized efforts to connect these facilities with PPE sources. Some of the private nursing homes with large corporate structures also reported constant access to valuable information and advice as their home offices arranged dissemination of information regularly. The clearest gap shown by the pandemic was how assisted living facilities serving adults with mental illness were left behind. The administrators for the ALFs had no source of information and no clear idea who was even supposed to answer their questions. When the state created a PPE portal several months into the pandemic to help residential facilities meet their PPE needs, there was apparently no effort to alert the ALFs to the existence of the portal; some of the ALFs learned about the portal's existence only due to Disability Rights Nebraska calling to interview them.

Later Pandemic Needs Identified by Surveys

By approximately June 2020, our surveys were revealing that basic access to food and PPE had stabilized and most staffing ratios were back to pre-pandemic levels, but new unmet needs had emerged that remain a challenge even now.

“It’s inexplicable: everyone knows these are the folks most at risk, but there was just no plan to test them.”

Visitation

All facilities have struggled with the competing needs to keep their residents safe from transmission and the basic human need to see one’s family, friends and neighbors to maintain good mental health¹². One nursing home administrator told us “We’re saving their bodies, but I fear we’re killing their spirit. You can just see them wilting from the lack of human interaction, and while staff is trying hard, we can’t be in everyone’s room enough to make up for their family and friends.” Changing [guidance](#) from the federal government has meant some restrictions on visitation have begun to loosen¹³, though as discussed below that may hinge upon adequate testing. Some facilities have allowed for visitation by family members by going outside, remaining at least 6 feet apart the entire time, and all parties wearing masks.

Testing and Transportation to Testing

The TestNebraska program has left behind Nebraskans with disabilities across the board and has led to Disability Rights Nebraska filing a [complaint](#) with the U.S. Department of Health and Human Services’ Office for Civil Rights (OCR) about the program’s inaccessibility for people who are blind or who lack the ability to drive themselves to a testing site.

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By failing to make reasonable modifications to the Test Nebraska program, the State is discriminating against individuals with disabilities who are being denied equal access to participate.”

Excerpt from our
Office of Civil Rights
complaint, June 2020

Particularly frustrating was the state’s long refusal to provide in-house testing for elderly people in nursing homes, vulnerable adults living in group homes for those with developmental disabilities, or Nebraskans living in group homes for people with mental illness. One ALF administrator said “I’m tearing my hair out. None of the people living here have a car, and I can’t even fit them all into my personal vehicle. The National Guard is going from town to town—why can’t they just send someone over here to test us all at once since we can’t get to them?” One of the nursing home officials told us “Our elderly residents are simply too frail to be transported to a National Guard testing site. The state hasn’t given us any explanation how they’re going to test our vulnerable people, so we’ve just made private arrangements to contract with a testing service. It’s inexplicable: everyone knows these are the folks most at risk, but there was just no plan to test them.”

The lack of testing in congregate facilities is particularly concerning in light of how reopening visitation hinges upon how long the facility has been free from a new COVID-19 case. To put it another way, without testing all residents and staff, there is no objective basis to begin reinstating visitation safely, yet many facilities began re-opening visitation since no one was showing symptoms. Given the large number of asymptomatic COVID-19 carriers that have been a hallmark of this pandemic, the lack of testing except when symptoms show is poor policy and defies the recommendations of the Center for Disease Control (CDC) and medical experts.

Lack of Information from the State

The information gap that left out facilities providing service for those with mental illness has remained a constant even through to the date of this report. Visitation regulations were at least spelled out clearly for facilities serving the elderly and adults with developmental disabilities, but the ALFs were left without any clear guidance on visitation policies for their residents. Our surveys revealed some ALFs simply cancelled all visitation—even window visits—while others were allowing their residents to engage in group activities without any change.

The Divide in Care among Different Groups of People with Disabilities

A particular concern is the wide gap between how the state responded to providing for different types of disability. A clear pattern emerged across the state: those with developmental disabilities or intellectual disabilities received the most robust access to state expertise and aid and those with mental illness received the least care.

Adults with mental illness are the clearest example of the state's failure to consider in disaster planning and must be a center point for future work.

Developmental Disabilities Needs

The Nebraska Developmental Disabilities Division understood the risks posed by COVID-19 and quickly established recurring calls with stakeholders to provide updates on the Division's COVID-19 activities, share data, and take questions. While we applaud the Developmental Disabilities Division for their diligent and ongoing information sharing efforts, we remain concerned by the state's decisions related to testing. Unfortunately, the initial testing scheme was only testing those who were symptomatic. Testing of asymptomatic individuals did not begin until mid-June 2020 and was still voluntary despite CDC recommendations to conduct uniform testing. While the Division did commit to helping those providers, guardians, or individuals who want to get tested through the TestNebraska system, testing of program participants and staff at both community providers and the state-operated Beatrice State Developmental Center is still not compulsory as of the date of this report.

Elderly and Aged People in Nursing Homes

Our surveys revealed that nursing homes and long term care facilities struggled without much state help; they were not provided with the sort of information sessions offered by the Developmental Disabilities Division. These facilities were not entirely without resources, though, as they reported regular information access and help in obtaining PPE from their private industry association and occasionally from corporate partners. Local county health departments also were a lifeline for these facilities in meeting PPE needs, though in greater Nebraska there were gaps where local health initiatives have less funding or have been defunded.

Adults with Mental Illness in Assisted Living Facilities

By far, the population of adults with mental illness were those who were most left behind in the pandemic. We heard no reports of efforts by the Division of Behavioral Health to get information briefings to these facilities or to connect ALFs with PPE. Unlike the nursing homes, ALFs in Nebraska have no umbrella association that could step into the breach, leaving most of this vulnerable population in the gravest danger with food insecurity, no access to TestNebraska, and no PPE. Adults with mental illness are the clearest example of the state's failure to consider in disaster planning and must be a center point for future work.

Disability Rights Nebraska's Advocacy from the Monitoring Findings

As the surveys were conducted and common themes began emerging, Disability Rights Nebraska began reaching out to leadership at the Nebraska Department of Health and Human Services to lift up the concerns we were hearing in the field. Beginning in March 2020, Disability Rights Nebraska CEO Eric Evans regularly began presenting COVID-19 concerns in writing to DHHS CEO Dannette Smith. CEO Smith instituted periodic calls to allow Disability Rights Nebraska to describe what we had learned and to discuss remedies for unmet needs.

State Reforms to Applaud

As a result of the issues documented by Disability Rights Nebraska that were shared with DHHS leadership, the state made several laudable reforms including: creation of an online portal to request PPE, improved dissemination of information to congregate facilities to ensure accurate information was made available more quickly to all residential facilities particularly the assisted living and long term care facilities, ultimately expanding testing of residents in long term care facilities as well as the Beatrice State Development Center and the Regional Centers, and reinstating DHHS inspections of long term care facilities to ensure ongoing monitoring. Most recently, the state's written [vaccination plan](#) deserves acclaim for prioritizing the need to vaccinate "critical populations" including those in congregate facilities, the elderly, and those with complicated underlying medical conditions¹⁴.

One of the most significant accomplishments as a result of ongoing advocacy was having the state affirm that in the event of rationing of ventilators or medications, there would be a non-discrimination policy mirroring the guidance from the U.S. Department of Health and Human Services Office for Civil Rights. This was achieved after Disability Rights Nebraska reached out to the four major hospital systems in the state to inquire about their medical rationing plans and to educate them on the ethical materials developed by the National Disability Rights Network as well as legal guidance from the OCR. Disability Rights Nebraska then brought together 15 stakeholder organizations from across the state to publicly [call for guidelines](#) to ensure scarce resources would be provided in compliance with civil rights laws. In addition to these coalition partners, Disability Rights Nebraska worked with several individuals willing to share their lived experience with reporters to ensure that real Nebraskans stories were first and foremost part of the dialogue in traditional and social media.

We remain appreciative of CEO Smith's openness to dialogue about unmet needs and her willingness to designate staff to work with Disability Rights Nebraska over a period of months to discuss pandemic needs.

“CEO Smith's statement affirms the federal Office of Civil Rights guidance and should give comfort to the many Nebraskans we've been hearing from since the pandemic began. **This guidance may very well save lives.**”

Disability Rights Nebraska's CEO, Dr. Eric Evans

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Work Yet to be Done

At the date of this report, there are concerning areas where the state simply has refused to adopt common sense reforms that we continue to advocate for as best practices to protect Nebraskans with disabilities.

Data Transparency

Nebraska is currently reporting lump numbers by county, while several sister states have provided much better data transparency on outbreaks by specifically reporting per facility which permits the public and family members to fully understand risks. Other states, including our immediate neighbors [Colorado](#)¹⁵ and [Iowa](#)¹⁶ are both publicly sharing information that lists site-specific positive testing in Long Term Care facilities.

As the National Consumer Voice has [reported](#), many states are providing thorough data that allows the public to know where COVID-19 outbreaks have occurred¹⁷. Despite repeated requests by Disability Rights Nebraska, the state has refused to expand transparency on the information it has about outbreaks.

Comprehensive Testing

Nebraska needs to conduct comprehensive testing of all congregate facility residents per CDC recommendations. By June 2020, DHHS introduced the Baseline testing program that allowed Assisted Living Facilities and Nursing Homes the option to participate in baseline testing. Unfortunately, the only way to do the actual testing was in their own facilities with the aid of a registered nurse. Other facilities run by private entities—particularly Assisted Living Facilities for adults with mental illness—rarely have a registered nurse on staff. Although a significant number of congregate facilities participated in the testing program, not all were able to before the state suspended the program in October 2020; it is unclear what plans exist to resume testing as pandemic numbers soar¹⁸. According to state officials, the Nebraska National Guard has ceased providing assistance in testing programs, though this remains a viable solution to providing in-house testing for all congregate facilities.

Test Nebraska Accessibility

Despite ongoing negotiations with the state, TestNebraska remains a program only accessible to those with the ability to drive themselves to a testing site. Because that violates the state's obligations under the Americans with Disabilities Act (ADA) and other federal disability rights laws, Disability Rights Nebraska filed a formal [complaint](#) with the Office for Civil Rights in June 2020

How have other states made COVID-19 testing accessible?

Florida

In Broward and Miami-Dade County, modifications were made so that seniors and people with disabilities could be tested at home.¹⁹

Texas

In Houston, the Health Department paired up with a local medical start-up and their public transit authority to provide either transportation to a mobile testing site or if that is not feasible, the department can administer an at-home test.²⁰

Delaware

In early May, Delaware's Governor and the Delaware Division of Public Health (DPH) announced a plan to test all residents and staff of the state's long-term care facilities for COVID-19.²¹

in partnership with the Center for Public Representation and The Arc of the United States. The complaint was brought on behalf of seven nonprofit entities in the state as well as several individual Nebraskans with disabilities.

The complaint charged that the TestNebraska screening process via website was inaccessible for many people and that the drive-through mobile testing sites are inaccessible, leaving Nebraskans with disabilities without any means of using the program to test for COVID-19. The state expanded the screening process to permit a telephonic option after the complaint was filed, but subsequently and without any public notice, the state removed this option, citing the large volume of calls.

As of the date of this report, there has been no change to the drive-through mobile testing sites. Other states have successfully modified their drive-through testing programs so as not to exclude people with disabilities. For example, [in Broward and Miami-Dade County, Florida](#), modifications were made so that seniors and people with disabilities could be tested at home¹⁹. [In Houston, Texas](#), the Health Department paired up with a local medical start-up and their public transit authority to provide either transportation to a mobile testing site or if that is not feasible, the department can administer an at-home test²⁰. Many states provide testing at nursing homes and other long term care facilities²¹. Nebraska's failure to make these reasonable modifications, leading to the exclusion of individuals with disabilities from its testing program, constitutes discrimination based on disability.

Future Emergency Planning

Nebraska needs to ensure that written plans for a future emergency include planning for those with disabilities and formation of those plans should be done with the input of people with disabilities at the table. Whether it's another pandemic, a flood, or a tornado, there must be a clear explanation for which facilities must shelter in place and which should be evacuated. In the case of evacuation, most of those living in residential facilities will lack the ability to transport themselves and may have high needs for care after removal from their facility so the state needs to develop written protocols. After the formation of these plans in collaboration with people with lived experience of disability, the state must then inform all residential facilities who they can turn to for food insecurity or equipment needs and what they can expect in the case of either a shelter in place order or an evacuation.

Vaccination Distribution Planning

Initial reports about a COVID-19 vaccine suggest that administration of the vaccine may only occur at selected hospitals across the state. If true, this will again leave behind Nebraskans with disabilities and all of those unable to drive themselves to a hospital. The vaccination distribution plan must identify congregate living facilities as a priority and arrange vaccinations to be done on-site, and then individuals living independently but without transportation must be addressed as well.

Conclusion

Nebraskans are good neighbors who care for one another. In the earliest days of the pandemic, gaps in planning came to light that may have just been overlooked initially. Now, as we stand on a precipice of crisis, the divide of inequality is wider after months of inaction by state officials. We urge the state to adopt best practices with input from Nebraskans with disabilities to ensure that through the rest of this pandemic and in any future emergency, all Nebraskans regardless of their disability are valued and protected.

Endnotes

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- 7 As Nebraska’s Protection & Advocacy system, Disability Rights Nebraska is authorized to pursue legal, administrative, and other appropriate remedies to ensure the protection of, and advocacy for, the rights of individuals with disabilities. 42 U.S.C. § 15043(a) (2)(A). Disability Rights Nebraska operates seven federally funded protection and advocacy (P&A) programs. The P&A system is a nationwide network of Congressional created, legally based disability rights agencies. As the protection and advocacy system in Nebraska, Disability Rights Nebraska has the authority to provide legal representation and other advocacy services to people with disabilities.
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